
HIV/AIDS Care and Support Capacity and Needs in Zambia: An Assessment in Four Districts

Final Draft Report



National AIDS Council

VCT and Care Technical Working Group



Kara Counselling and Training Trust (KCTT)



TvT Associates Inc./The Synergy Project



Family Health International (FHI)/IMPACT Project



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ACRONYMS

AIDS	Auto-Immune Deficiency Syndrome
ARV	Antiretroviral drugs
AZT	Zidovudine
CBC	Community-based care
CBoH	Central Board of Health
CMAZ	Churches Medical Association of Zambia
CSO	Central Statistical Office
DAPP	Development Aid People to People
DATF	District AIDS Task Force
DDH	District Director of Health
DHMT	District Health Management Team
DHS	Demographic and Health Survey
DOT	Directly observed therapy
DOTS	Directly observed treatment, short-course
FGD	Focus group discussion
HAART	Highly active antiretroviral therapy
HBC	Home-based care
HEPS	High-energy protein supplements
HIPC	Highly indebted poor countries
HIV	Human immunodeficiency virus
IEC	Information, education and communication
IGA	Income generating activity
IMR	Infant mortality rate
MOE	Ministry of Education
MoH	Ministry of Health
MTCT	Mother-to-child-transmission
MTP	Medium Term Plan
NAC	National AIDS Council
NACP	National AIDS Prevention and Control Programme
NAP+	Network of African People Living with HIV/AIDS
NCH	Neighborhood Health Committee
NGO	Nongovernmental Organization
NICU	Neonatal Intensive Care Unit
NZP+	Network of Zambian People Living with HIV/AIDS
OVC	Orphans and vulnerable children
PALS	Positive and Living Squad
PEP	Post-exposure prophylaxis
PHC	Primary health care
PHMT	Provincial Health Management Team
PLHAs	People Living with HIV/AIDS (infected and affected)
PMTCT	Prevention of mother-to-child-transmission
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TB	Tuberculosis
TWG	Technical Working Group
U5MR	Under-five mortality rate
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
UTH	University Teaching Hospital
VCT	Voluntary counseling and testing
WFP	World Food Programme
WHO	World Health Organization
ZCC	Zambia Counselling Council
ZNZP+	Zambia Network of People Living With HIV/AIDS
ZVCTS	Zambia VCT Services

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Facilities visited:

Lundazi District

Lundazi District Hospital, Kanyanga, Mwase-Lundazi, Lumezi

Mongu District

Limulunga, Sefula, Namushakende, Mulambwa, Lewanika, Nalwei

Ndola District

Mushili, New /Main Masala, Lubuto, Railway Surgery, Twapia, Nkwazi

Lusaka District

Kabwata, Kamwala, Matero Main, Chainama, Chipata, M'tendere, Chilenje

Executive Summary

The Zambia Ministry of Health (1999) estimates that 1 million adults in Zambia have been infected with HIV, and that 300 to 500 people are infected every day. Every year, 99,000 Zambians die of AIDS. An estimated 21,000 children are infected in Zambia with HIV each year (MoH 1999). Transmission of HIV from mother to child is estimated to be 35 to 40 percent. *Children on the Brink, 2002* estimates 19.4 percent of Zambian children under age 15 will be orphans by 2005, and most of them will be maternal or double orphans. Most orphans and vulnerable children live below the poverty line, in a household with a surviving parent, relative, or grandparent.

Hospitals, clinics, and their staff have to cope with the increased demands for HIV and tuberculosis care. The proportion of beds occupied with persons having HIV-related illnesses has steadily increased and has reached 70 percent in many district and provincial hospitals. Absenteeism, attrition, and mortality among health care professionals have seriously affected capacity and quality of health care services.

ZAMBIA'S RESPONSE TO HIV/AIDS

Zambia has responded to the effects HIV/AIDS has had on individuals, families, and communities since the beginning of the epidemic in the mid-1980s. In its response, nongovernmental organizations (NGOs), the National AIDS Prevention and Control Program (NACP), bilateral donors, the World Health Organization (WHO), and other United Nations organizations have fostered a variety of activities to improve HIV/AIDS care and support to people infected and affected by HIV/AIDS (PLHAs).

The Zambia HIV/AIDS/STD/TB Strategic Framework for 2001–2003 is meant to offer broad strategic guidance and policy formulation for care and support. It calls for further strengthening of prevention and care and support activities. The framework identifies the following high-priority aspects of care and support:

- More voluntary counseling and testing;
- Better home-based care for people living with HIV/AIDS;
- Better drug supplies;
- Better hospital care; and
- Fewer stigmas.

Through policy guidance from the Ministry of Health (MoH) and technical guidance from the Central Board of Health and within the health reform framework, district health management teams are now responsible for HIV activities related to the health sector. These teams form district AIDS task forces in which public, NGO, and community representatives can partner to increase access to sexually transmitted infection (STI) care; control tuberculosis; strengthen condom promotion and distribution; provide voluntary counseling and testing (VCT), mother-to-child transmission (MTCT), opportunistic infection, and home care; and develop strategies to mitigate the impact of AIDS.

The framework for the multisectoral approach was established under the National AIDS Council (NAC) in 1999. The framework emphasizes the need for VCT, facility and home-based care, medication and supplies, and a special effort to address stigma. The

NAC coordinates the activities of 14 line ministries and other actors, such as NGOs and community-based organizations (CBOs).

Voluntary counseling and testing services are currently being provided at more than 40 sites in all districts. As a consequence of health reform, district health management teams and district AIDS task forces are promoting linkages among VCT services, medical and home-care services and social support services, and support groups for PLHAs to create the provision of comprehensive care across a continuum.

The current Zambia HIV/AIDS/STD/TB Strategic Framework does not provide detailed guidance or standards for program planners and implementers. The framework also does not incorporate some important recent developments such, as therapies to prevent mother-to-child transmission of HIV and opportunistic infections, nutritional support, and safe and effective use of antiretroviral drugs. Stigma has been discussed only in general terms.

ZAMBIA HIV/AIDS CARE AND SUPPORT ASSESSMENT

The National AIDS Council initiated this assessment through its VCT and Care Technical Working Group. The objective of the assessment was to identify the scope and capacity of the current provision of HIV care and support at sites in two rural districts (Lundazi in Eastern Province and Mongu in Western Province) and two urban districts (Ndola in Copperbelt Province, and Lusaka, in Lusaka Province). The four districts have a combined population of 1,900,545, or approximately 20 percent of the total population.

The Technical Working Group requested the assessment team to research the needs of districts, known for their HIV care and support activities, for meeting a set of minimal HIV care standards. The working group believed existing care and support standards were able to meet basic medical, social, and psychological needs of affected families. As one outcome of the study, the group hoped to be able to define a standard package of HIV care and support at the district level in line with the activity plan of the Zambian Strategic Framework 2001-2003.

KARA Counseling and Training Trust was the operational arm of the assessment. Key members of the Technical Working Group, national public health consultants, TvT Associates provided consultancy support; with technical advice from Family Health International. USAID Zambia provided financial assistance.

The objective of the assessment was to identify opportunities and challenges in HIV comprehensive care and support to design district-based relevant HIV comprehensive care packages to improve the quality of life of people living with HIV/AIDS. Such standard packages will assist Zambia in meeting NAC's goals, as outlined in the National Strategic Framework 2001-2003.

The assessment was implemented using the following steps:
Collection and review of literature and other documents on care and support in Zambia;

Selection of districts and sampling sites to implement the assessment;
Completion of quantitative data and collection interviews with HIV/AIDS health care providers and community members;
Conduction of structured interviews with district health management teams in selected districts; and
Completion of focus group discussions and/or in-depth interviews with institutional health services providers, community-based health service providers, and people living with HIV/AIDS.

Eight types of health facilities were included in the assessment: referral hospitals, general/district hospitals, mission hospitals, urban hospitals, rural health centers, private clinics, hospices, and VCT facilities.

Between January and March 2002, the survey site facilities and programs were visited. A total of 545 health care providers completed the questionnaire. Seventy-two focus group discussions (Lundazi, 19; Lusaka, 24; Mongu, 8; and Ndola, 21) and 38 in-depth interviews (Lundazi, 12; Lusaka, 8; Mongu, 6; and Ndola, 12) were held with more than 500 health professionals, community health providers, and people living with HIV/AIDS.

TRAINING OF HEALTH CARE WORKERS

Most respondents to the health care workers survey were nurses (80 percent), followed by clinical officers (14 percent), medical doctors (5 percent), and social workers (1 percent). With new developments constantly emerging in the area of care and support for HIV/AIDS patients, respondents indicated they view in-service training as an important avenue to further enhance their skills and knowledge.

In-service training in which respondents had participated ranged from counseling training that lasted for more than two weeks (43 percent), to training in the provision of social support (12 percent), the least reported topic area. Other areas included clinical management (40 percent), STI syndromic management (27 percent), tuberculosis management (28 percent), and MTCT (30 percent).

Many health care providers and community members were interviewed in focus group discussions to obtain their opinions and perspectives on specific issues related to HIV/AIDS care and support activities. Several health workers said they have received training in counseling, home-based care, and AIDS management. They expressed the need for more training in counseling, particularly to meet the special needs of adolescents whose parents are infected with HIV and HIV-positive individuals.

Those who had received training believed clients' needs had changed since their pre-service training; they now require additional training to meet new challenges. Doctors said they had little opportunity for formal counseling training. As a result, they often write a lab request for an HIV test without discussion because they do not know how to talk with people about the implications of testing.

Counselors who participated in the focus group discussions said they receive generic training, but require further training in counseling interventions for specific client needs. Training opportunities listed by community members included behavior change, leadership skills, hygiene, administration of directly observed therapy short-course for tuberculosis, home remedies, and nutrition. Community members said the added value from the training was being able to use the information when they talked to their children. Community health providers and people living with HIV/AIDS said they need a variety of information, including how to address nutrition in HIV/AIDS-affected households.

CLINICAL CARE

More than two-thirds (69 percent) of clinical HIV service providers said voluntary counseling and testing services are provided at the facilities where they work. Respondents from rural health centers were least likely to be working at locations with VCT services: almost one-third (29 percent) said VCT services were not available at their facility. Acceptance of VCT by patients was perceived to be sporadic, with only 30 percent of clinical providers saying testing was always accepted when offered to patients. Among parents who were offered testing for themselves or their children, only 13 percent of respondents said the offer was always accepted.

Only 16 percent of respondents provide any form of ARV therapy to patients, compared with a much higher rate of provision of micronutrients (64 percent). ARV treatment of children with HIV/AIDS was also limited; only 12 percent of HIV clinical care providers offered ARV therapy to children with HIV/AIDS. More than two-thirds of these workers said additional training in ARV therapy is required for them to adequately perform their job.

In the four districts covered by the assessment, 56 percent of clinical care workers in Ndola, 25 percent in Lusaka, 17 percent in Lundazi, and 12 percent in Mongu reported that they provide tuberculosis preventive therapy to patients. Clinical and tuberculosis guides are reported to be available by less than half the clinicians throughout all facilities.

NURSING CARE

The results in the four districts covered by the assessment indicate enrolled nurses in Lundazi (75 percent) were more likely to have received in-service training. In Ndola, Lusaka, and Mongu, a larger proportion of registered nurses reported that they had participated in in-service training.

In focus group discussions, several nurses reported providing home-based care. By doing so, they receive favourable shifts, allowances, access to workshops, and other benefits. A program manager reported nurses provide care to clients outside their catchment area to receive allowances. During these discussions, the nurses also confirmed the lack of training in counseling skills, citing one reason to be the length of time since many of them had been trained, which for some was 15 to 20 years.

Nurses in focus group discussions also indicated they provided tuberculosis care for home-based care patients, or in a hospice or health institution. Other services include

offering palliative care and VCT; forming post-test clubs; offering spiritual counseling; giving medication; providing food; washing patients; and distributing condoms, information, education, and communications aimed at stigma reduction

TUBERCULOSIS CARE

In the survey of HIV care providers, more than half of the respondents reported they provide tuberculosis care. More than two-thirds of respondents in referral hospitals, general hospitals, urban health centers, and VCT centers reported that in recent years, they have witnessed a sharp increase in the number of tuberculosis patients in their facilities, reflecting the nationally reported increase of reported tuberculosis cases.

Tuberculosis care providers (57 percent) in Lundazi were more likely to routinely provide VCT for HIV to patients. One-third of those in Lusaka and Mongu also reported they routinely provide VCT to their patients, and 41 percent in Ndola also reported they routinely offer this service. Except for Lundazi, the majority of tuberculosis clinicians do not think it is their job to provide counseling and testing. This is in line with the focus group discussions among clinicians indicating a great need for counseling and training in breaking bad news. They said, “We don’t know how to talk to people about the implications of testing.”

Drugs for treating HIV/AIDS/TB patients are not readily available in several health facilities. Eighty percent of HIV care providers who provide tuberculosis care say they never provide tuberculosis prophylaxis; while 12 percent say they sometimes do; and 4 percent say they always make prophylaxis available to patients. According to 60 percent of clinical care workers surveyed, insufficient drugs, and lack of training and policy guidelines, are the primary reasons tuberculosis prophylaxes are not provided to HIV/AIDS/TB-infected patients.

The majority of respondents who provide tuberculosis care in Ndola (84 percent) and Mongu (74 percent) routinely provide DOTS to patients. In Lundazi (57 percent) more than half provided this service, while in Lusaka 47 percent say they routinely provide DOTS. It is striking that a large proportion of tuberculosis clinicians in all districts do not provide DOTS as part of their responsibility.

PREVENTION OF MOTHER-TO CHILD TRANSMISSION

Mother-to-child transmission (MTCT) is the primary route of HIV infection in children, and programs to reduce transmission have started as pilot projects throughout the country during the past three years. Training in the provision of MTCT care was relatively high among respondents who provide these services, with 75 percent of those who provide MTCT care and support reporting that they received an average three weeks of training in counseling to prevent MTCT. The most common services reported were infant-feeding counseling (74 percent) and pre- and post-VCT counseling (66 percent). Less than half provide assistance with feeding formula (44 percent), ARV therapy (42 percent), or referral to other community services (42 percent).

ARVs have also been found to be effective in reducing the risk of HIV transmission between mothers and their babies. Among respondents who reported they personally provide prevention of mother-to-child transmission services, only those in Lusaka (77 percent) and Ndola (12 percent) reported they provide antiretroviral drugs to their patients, as the pilot MTCT sites in these two districts include these drugs.

More than half of all survey respondents who provide MTCT care and support identified the following as the main obstacles to improving and expanding MTCT services: shortage of staff (66 percent), shortage of equipment (60 percent), and stigma (57 percent).

In focus group discussions, participants said there was the lack of MTCT information at community levels on the effectiveness of current interventions to reduce MTCT. Knowledge levels, however, were higher in the catchment areas of the specific pilot studies on MTCT in Lusaka and Ndola. Community stigma was expressed by many for women returning home from the ANC with formula supplies being perceived as being HIV-infected

COUNSELING

One in five health care workers surveyed reported they provide counseling services to HIV/AIDS patients. A large proportion (86 percent) of those who provide counseling indicated counseling services are formally recognized in the health facilities where they work. Health care workers indicated more training would be required for them to adequately counsel patients. Among those who provide counseling, 39 percent reported they had received in-service training in counseling for more than two weeks, suggesting the majority provide counseling without adequate training.

Most health facilities provide a private space within the facility for counseling patients. Most respondents (68 percent) indicated counseling takes place in a special room in the facility. Counseling service providers reported they spend an average 28 hours a week counseling HIV/AIDS patients, and see an average 12 clients per week. Almost two-thirds of respondents who provide counseling services reported they also provide services after their regular working hours.

Couples counseling reduces the risk of couples having unprotected sex with their spouses, especially in the cases of discordant couples. The survey suggests that recommending couples counseling to patients is not standard practice. Only 9 percent of respondents said they "always" recommend counseling for couples, while the vast majority (77 percent) said they "sometimes" recommend couples counseling.

Respondents who provided counseling indicated many reasons patients visit them for counseling. In Ndola (95 percent), and Lundazi (89 percent), the reason given by most respondents was patients wanted to know their HIV status. In all four districts, clinicians are the most common source of referrals to counselors. In Mongu, 86 percent of those who provide counseling services reported they had been referred patients by clinicians. It was also the most frequent source reported by counselors in Lusaka (79 percent), Ndola

(75 percent), and Lundazi (47 percent). The data indicate the importance of having trained counselors within the district health system. The also suggest clinicians are not doing counseling, but rather referring clients to a trained professional counselor.

The focus group discussions with care providers indicated many reasons patients seek counseling: from illness-related to “want to know” in order to plan for the future. Again, community HIV caregivers mentioned they often refer community members to go for VCT. Care providers also mentioned resistance to testing was common, for such reason as fear of rejection, fear of early death, lack of trust in confidentiality, and poor accessibility of sites. People in focus group discussions living with HIV/AIDS were satisfied with the counseling services they currently receive.

Almost two-thirds (64 percent) of counseling service providers described their role as “stressful.” However, very few facilities have systems in place to deal with stress. Thirty percent of workers who provide counseling reported their institution provides support such as counseling to deal with work-related stress.

HOME-BASED CARE

Zambia has pioneered and expanded home-based care for HIV/AIDS patients during the past 15 years. Hospital units often initiated home-based care as an outreach service, but more community initiatives have evolved. Twelve percent of health care workers surveyed reported they provide home-based care services to HIV/AIDS patients.

A large proportion (77 percent) of home-based care providers say that the services they provide were initiated by the community, compared with 16 percent of providers whose services were initiated by a health facility. Provision of home-based care services is a fairly recent phenomenon for these health care workers. They have been providing home-based care for an average three years. Eighty-four percent have provided home-based care for less than five years. Respondents provide home-based care services as part-time work (74 percent), or unpaid volunteer work (52 percent). On average, home-based care workers reported they provide services to eight homes in their community per day. In all four districts home care providers provide care to a large number of clients per day. Half of those in Lusaka, and 46 percent of those in Mongu provide care to more than 10 clients daily.

In the focus group discussions, home-based care providers say the same client is visited usually once a week or every two weeks, except during serious illness when clients can be visited up to twice a day. The figures show, however, that with such a high caseload per home-base care provider, quality time spent with clients could be low.

To qualify for home-based care services, the patient must have a long-term illness (89 percent), or be in an advanced stage of a disease resulting from HIV (84 percent). Patients to whom services are provided have a broad range of physical, psychological, social, economic, and spiritual needs.

In all four districts, the most important needs of home-based care patients cited by care providers are: food (97 percent), drugs (84 percent), help with infection (70 percent), and emotional support (64 percent). Slightly more than half of these providers also cited clothes, money, and assistance in fighting stigma. These needs were confirmed in the focus group discussions in all places. In addition, both home caregivers, as well as PLHAs, mention the emotional needs such as companionship, prayers, respect and feelings of worthiness. Both groups mention the need for financial support to pay for transport and medical facilities and to buy drugs.

The capacity for referral from home-based care to medical or social support facilities was found difficult or nonexistent. Although at the community level, care providers cited: networking among various care provider programmes within the community was good; referral outside the immediate community was hampered by lack of directories (“who provide what and where”); and lack of involvement of others beyond the health sector.

LABORATORY SERVICES

Five percent of survey respondents indicated that lab services are provided at the facilities where they work. These facilities provide a broad range of lab services, including syphilis tests (86 percent), gram stains (79 percent), sputum smears (76 percent), standard hematology (69 percent), HIV ELISA tests (69 percent), and HIV rapid tests (66 percent).

At most facilities, same-day test results are available. Eighty three percent of respondents also reported some tests are referred to other laboratories. The most often referred tests include CD4 alternative microscopy, cited by 75 percent of respondents, and CD4 FACS, mentioned by 67 percent of respondents.

PHARMACY SERVICES

Twelve percent of respondents reported they provide pharmaceutical services at their health facilities. The main sources of drug supplies for these facilities are the provincial or district stores (64 percent), followed by the central medical stores (28 percent), religious organizations (12 percent), and NGOs (11 percent). A much smaller proportion of respondents reported their facilities obtain drugs from private donors (7 percent), foreign governments (7 percent), or private companies (4 percent). Most respondents (81 percent) who provide pharmacy services indicated they receive the essential drug package, however, less than half (44 percent) reported the package always arrives on time. Only one-third (34 percent) indicated the package is complete upon arrival.

All of the respondents who provided pharmacy services at various sites in Lundazi reported that the tuberculosis drugs, rifampicin, ethambutol, pyrazinamide, and streptomycin, were in stock at the time of the survey. In other districts, but in particular in Mongu, many respondents mentioned the unavailability of essential drugs for tuberculosis control. Many respondents mentioned streptomycin to be out of stock.

Participants in the focus group discussions also raised the issue of drug affordability by PLHAs, including the essential tuberculosis drugs. Participants indicated drug

requirements, even inexpensive drugs, over time require substantial household expenditures. In all focus group discussions, the cost of drugs was an issue, although the exemption possibility was mentioned. The exemption possibility is hardly used as it discloses the serostatus to the drug dispenser. Also discussed were drug unavailability, strong painkillers, irregular tuberculosis and other essential drug supply, and the fact that peripheral health care staff cannot prescribe strong painkillers, such as codeine or oral morphine, for palliation.

ADMINISTRATION AND FACILITY MANAGEMENT

Sixty-seven respondents, representing 52 facilities surveyed, work as administrator or manager of a health facility. These respondents provided insight into management of each health care facility and the ability of the facility to deliver HIV/AIDS care and support services.

Common funding sources identified by health administrators included the Government of Zambia (82 percent), local sources (40 percent), and NGOs (25 percent). Sixty-seven percent of respondents also reported that patients pay attendance fees. Fees were also reported for laboratory services (60 percent), surgery (40 percent), and antenatal services (21 percent).

Two-thirds of administrators/managers reported their facilities have in-patient wards, and during the year prior to the survey, an average 65 percent of female and 60 percent of male inpatient beds were occupied. The majority of administrators (79 percent) reported that ambulatory patients with known HIV-related illnesses attend the general outpatient clinic at their facilities, the VCT center (31 percent), or a home-based clinic (30 percent).

National guidelines on HIV/AIDS care and support were not universal in the health facilities. Fewer than half of administrators reported their facility follows national guidelines on MTCT (49 percent), clinical management of HIV/AIDS (48 percent), VCT (45 percent), HIV/AIDS reporting requirements (39 percent), and home-based care (27 percent).

In Zambia, district AIDS task forces provide an avenue for planning interventions to respond to the HIV/AIDS pandemic. District health management teams convene AIDS task forces to plan projects in accordance with the national strategic framework on HIV/AIDS. According to the administrators, 24 percent indicated the facilities where they work have received guidance on the National AIDS Strategic Plan. Twelve percent of these respondents said they had participated in HIV/AIDS planning with the district task force, and 22 percent said they had participated in HIV/AIDS planning with the district health management team. The data show the medical facilities are not yet regular partners in the district health planning process.

When asked about the biggest obstacles to improving and expanding HIV/AIDS care and support in the facilities where they work, insufficient training (72 percent) emerged as the most common obstacle. Other obstacles mentioned by more than half of respondents

included staff shortage (66 percent), lack of HIV/AIDS guidelines (57 percent), and low salaries (52 percent).

STIGMA

HIV/AIDS-related stigma is both widespread and a significant obstacle to the provision of effective care and support measures. Stigma can occur at several levels: political, institutional, social, and psychological. All respondents were asked a series of questions to determine the level of HIV/AIDS-related stigma within care and support services.

More than two-thirds (70 percent) of respondents said they spend more time with a patient suspected of having an HIV-related illness compared with a patient who has another illness.

Testing and receiving test results is a sensitive process and could signal the beginning of HIV-related stigma, especially if an individual tests positive. Among HIV care providers, 25 percent said it is their job to disclose HIV test results to patients. Among all doctors, 48 percent disclose test result. Only 17 percent of clinical officers reported they disclose test results. However, 31 percent of nurse midwives, and 21 percent of enrolled nurse midwives provide test results.

Disclosure of HIV diagnosis to close relative of patients who are discharged from the hospital with late-stage clinical AIDS was not common among the health care workers surveyed. Only 9 percent indicated family members were informed of the HIV/AIDS status of the patient when released from the hospital. Patients are usually released if they improve clinically or recover (59 percent), or after agreeing to home-based care (20 percent). Most respondents (61 percent) thought that the current quality of care for patients at their facility was better than before, while 20 percent thought it had remained the same. Sixteen percent believed quality of care had declined at their facility.

Health care providers described the psychological impact of HIV status disclosure on patients in different ways. Only 30 percent of respondents described the patient as "easily accepting" the test results. Seventy percent of respondents described the patients as "depressed, with suicidal tendencies," 57 percent described the patients as being "in denial," and 42 percent said their patients often develop a feeling of "blame and condemnation" following a positive test result.

Few health care workers know their own HIV status. Fear of negative reactions from their colleagues or friends (73 percent) was most often cited as a reason for this lack of knowledge, followed by the opinion that there is no point in knowing one's HIV status if ARV treatment is not available (47 percent).

Fewer than half (48 percent) of respondents indicated their facilities had health worker protocols or guidelines on how to avoid accidental HIV infection. Health workers indicated no significant difference in behavior when examining or washing a patient with HIV versus a patient without HIV. In both cases, a large proportion of respondents said they wear gloves when examining an HIV-positive patient (86 percent) or a patient

without HIV (83 percent). Treatment of exposure to HIV is limited in the health facilities; only 5 percent of respondents said their facility provides ARVs to health care workers if they are exposed to the virus during the performance of their duties.

Most respondents (74 percent) believe that, compared with the past, the attitude had improved among staff within their facility toward patients with suspected HIV-related illness. This improvement resulted from acceptance of HIV/AIDS as part of their job (88 percent), and reduction in stigma of HIV/AIDS patients (60 percent).

SUPERVISION

Two-thirds of the 545 respondents reported they are supervised regularly on the job. In the three months prior to the survey, these health care workers had been visited by their supervisors an average 21 times. However, about one-quarter (24 percent) of them were visited by their supervisor only once during the same three-month period. Respondents cited the following reasons for their most recent supervisory visit: to discuss work-related problems (76 percent), to observe job performance (72 percent), to review reports (63 percent), and to provide work-related technical updates.

Respondents also identified the most difficult problems they face in performing their job. Difficulties mentioned by more than half of respondents included: staff shortages (78 percent), inadequate salary (69 percent), lack of supplies and/or stock (65 percent), demoralized staff (59 percent), lack of training (57 percent), inadequate facilities (52 percent), and inadequate transportation for patients.

Zambia Standards for Comprehensive HIV/AIDS Care and Support

VCT and care and support stakeholders in Zambia developed recommendations in a series of meetings that were held to review and further analyze the results of the assessment. The participating stakeholders included participants from the districts where the assessment took place, members of working groups for OVC, STI, IEC, PMTCT, and VCT, funding agencies, and other health officials in Zambia. The participants identified standards for comprehensive HIV/AIDS care and support in Zambia, a district level care and support package, as well as national recommendations for the National AIDS Council.

The following recommendations were offered towards establishing a comprehensive HIV/AIDS care and support package in Zambia.

- HIV care and support to be comprehensive: meeting medical, nursing, psychological, nutritional, social, economic and spiritual needs, while respecting client rights and promoting prevention opportunities throughout;
- Care providers to embody empathic attitudes, respect, and compassion;
- Comprehensive care to extend beyond the individual to the family or household;
- Comprehensive care to extend beyond the ill to asymptomatic infected people and address nutrition, prevention, and emotional needs;
- A key entry point to prevention and care and support to be voluntary, counseling, and testing;

- Medical services to include acceptable, affordable, and standardized preventive therapies; management of HIV-related illnesses and opportunistic infections; DOTS for HIV/TB; laboratory services; highly active antiretroviral therapy (HAART); post-exposure prophylaxis (PEP) for injuries and rape; STI management; and palliative care;
- Reproductive health services to include VCT, antiretroviral drugs to reduce mother-to-child transmission of HIV, safe labor practices, follow up care for HIV-positive mothers and infants, infant feeding counselling and family planning;
- Workplace safety to be ensured at each health care facility for staff and patients, including care for the care providers and opportunities for VCT for staff at relevant places;
- Health and community care providers to have relevant counselling, communication, and supervisory skills, through adequate training and follow-up training as per national policies, guidance, and norms;
- Care services to be delivered across a continuum of care from home-care programs and organizations to facility programs and back through functional referral and feedback mechanisms with client's consent;
- HIV care planning to involve all sectors—line ministries, NGOs, faith-based organizations, and CBOs—with particular attention to be given to vulnerable groups and gender issues; and
- PLHAs to be involved in planning and implementation.

6.2 Zambia HIV/AIDS Care and Support District Package

- A functional and multisectoral DATF with mandated planning, coordination, and dissemination responsibilities answerable to district authorities;
- Ongoing partnerships through DATF between public health, hospital, private, faith-based, nongovernmental, community-based and home-care programs, and organizations and providers of comprehensive care and support;
- Updated directories of HIV care services—who does what and where across a continuum from institutions to community-based and home-care programs;
- Accessible and affordable facilities for physical therapy, opportunistic infections management, STI, HAART, PEP, and palliative care;
- Health care facilities that address care for the HIV care providers;
- District health plans that support to health programs that include activities to scale up VCT, MTCT and home care;
- VCT activities that include active referral to care and support (VCT PLUS), links to MTCT, promotion of couple counselling, and opportunities for health care staff to learn their serostatus;
- TB-DOTS activities linked to VCT;
- MTCT activities integrated with VCT and reproductive health services;
- Accessible facilities to address needs of HIV-asymptomatic people, such as reproductive health, nutrition, healthy life styles, and preventive therapies;
- Nutritional support activities for families affected by HIV to be addressed by relevant district bodies;

- Training activities for each care provider cadre that reflect specific needs in care and support;
- Expanded availability of drugs, particularly, antifungals, strong analgesics, and antiretrovirals;
- Promotion of government policy for fee exemptions to HIV/AIDS health services;
- Management and referral systems to support the continuum of care;
- Availability of guidance materials and national policies and standards for HIV/AIDS at all health facilities and HIV/AIDS programs; and
- Monitoring and health management information systems in place for HIV/AIDS care and support activities

6.3 National Recommendations

The VCT and Care Technical Working Group proposes the following recommendations for the National AIDS Council:

1. Adopt the Zambia Standards for Comprehensive HIV/AIDS Care and Support and the Zambia Essential HIV/AIDS Care and Support District Package and incorporate them into the National HIV/AIDS/STD/TB Strategic Framework;
2. Include counselling skills in the preservice training for all categories of nurses;
3. Provide training in communication skills to doctors and clinical officers that offer HIV/AIDS diagnostic and treatment services to improve their ability to ‘break bad news’ to clients;
4. Continue to educate clinical care providers to meet the challenges of HIV/AIDS clinical management and care provision. Revise curriculum for pre- and in-service training to address preventive therapies for opportunistic infections, management of all AIDS and HIV/AIDS-related illnesses, the safe and effective use of antiretrovirals, issues of drug adherence to long-term drug taking, and referral mechanisms;
5. Give providers of clinical care, counselling, and home care access to up-to-date, relevant, and appropriate national guidelines and learning materials;
6. Recognize counselling a profession, with all its benefits and responsibilities;
7. Include in the Zambia Essential Drug Package antivirals, for example, acyclovir; antifungals, for example, fluconazole; analgesics, for example, codeine and oral morphine; and antiretrovirals, including HAART;
8. Lobby for the adoption of a parliamentary act that will make strong analgesics, such as codeine and oral morphine, available for palliative care to relieve the pain and suffering of those with afflictions related to HIV;

9. Include in the guidelines of the District Aids Task Force, the following roles and responsibilities:
 - a) The DATF to be answerable to the District Development Coordinating Committee; and
 - b) The DHMT to act as the secretariat for the DATF;
10. Include total lymphocyte counts and alternative CD counts in district-level laboratory services to meet the current needs related to HIV/AIDS care; strengthen systems for quality assurance at all levels;
11. Assist with the current staff shortages and health services overload, promote strategies that focus on early disclosure (with the consent of the client) to significant others, such as a trusted relative, parent, sibling, children, and/or partner to:
 - a) Help clients to cope better;
 - b) Encourage clients to seek assistance earlier for opportunistic infections and other HIV/AIDS-related conditions;
 - c) Assist patients to adhere better to drug treatment; and
 - d) Share future planning for children;
12. Incorporate data on AIDS and HIV/AIDS-related illnesses in routine records and reporting systems to strengthen health management systems at all levels;
13. Develop practical and feasible systems for supervising institutional clinical HIV/AIDS care, counselling, and home care services; and
14. Promote partnerships between various institutions and programs that provide care and support services to collaborate better and design referral mechanisms for clients across a care continuum from home to community to facility and back.

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CHAPTER ONE

BACKGROUND AND INTRODUCTION

The population of Zambia is estimated at slightly more than 10 million. Between 1990 and 2000, the population grew at a rate of 2.9 percent a year, compared with the 1980–1990 growth rate of 3.1 percent a year; this represents an annual population decline of 6.4 percent¹.

Zambia is one of the most urbanized countries in Africa. About 90 percent of the population in Copperbelt Province and 95 percent in Lusaka Province live in urban areas (Nsemukila, B.G. 1998). The formal sector offers limited employment. Poverty levels are higher in rural areas than in urban areas, with an overall rate of 73 percent².

1.1 Health Services

The Government of Zambia is committed to ensuring that health services are available to everyone, to reducing mortality and morbidity, and to improving the general health of all Zambians. To this end, the health system has been decentralized. Districts are now responsible for planning, implementing, and monitoring primary health care (PHC) programs, and they use a district essential care package as a framework for planning.

1.2 Institutional Framework

District and provincial Health Management Teams (HMT) administer health services. District teams plan and administer local health services. They coordinate multisectoral health issues and they train district staff. Provincial health teams support the district teams and supply them with equipment, drugs, and vaccines from the national supplies. The Central Board of Health (CBOH) manages the health sector and is responsible for the quality of health care services. The Ministry of Health (MOH) is responsible for the development of the national health policy, strategic planning, the implementation of legislation, resource mobilization, and external relations. Health services are provided at six levels: community interventions; health posts; health centres; and first- (district), second- (referral), and third-level hospitals. Mission hospitals are considered to be part of the National Health Service and fit within that structure. Some districts have active Neighbourhood Health Committees (NHCs) that interface between the community and the local health institutions. Zambia also has many private health institutions that offer a variety of services; most are found in urban areas. Lusaka has more than seventy clinics and hospitals that offer services to the public.

The 1,800-bed University Teaching Hospital has seen rising admissions, a longer bed occupancy rate, and a high hospital mortality rate. In 2000, pediatric admissions numbered more than 20,000 in the children's wing, excluding Neonatal Intensive Care

¹ Preliminary Report, 2000 Census

² Living Conditions Monitoring Survey, 1998

Unit admissions. The major causes of admissions and deaths among children were acute respiratory infections, malaria, anemia, diarrheal diseases, malnutrition, tuberculosis (TB), meningitis, and septicemia. The overall hospital mortality rate during the same period was 20 percent. (University Teaching Hospital, Health Information Unit, Annual Report 2001) The Zambia mortality rate for women is 10.61 percent and for men 11.32 percent. (DHS 1996)

CHAPTER TWO

THE IMPACT OF HIV/AIDS ON HEALTH

The human immunodeficiency virus/auto-immune deficiency syndrome (HIV/AIDS) is underreported and poorly diagnosed in Zambia. However, data collection systems at the University Teaching Hospital in Lusaka provide reliable information on disease trends and disease presentation. The hospital serves as a referral health facility for more than 1.5 million people in greater Lusaka. It is the only tertiary hospital in Zambia, and it has borne the bulk of HIV/AIDS clinical cases. Therefore, morbidity and mortality figures recorded at the hospital represent the national urban status of the disease.


It is estimated that one million adults in Zambia have been infected with HIV, and that 300 to 500 people are infected every day. Every year, 99,000 Zambians die of AIDS. *Children on the Brink*, 2002 estimates that by 2005 19.4 percent of Zambian children under age 15 will be orphans, and a large majority of them will be maternal or double orphans. The majority of orphans and vulnerable children (OVC) live below the poverty line, in a household with a surviving parent, relative or grandparent.

The first case of HIV in Zambia was clinically confirmed in 1984. Approximately one million adults in Zambia have probably been infected with HIV, and an estimated 300–500 people are infected every day. In 1998, the estimated national HIV prevalence rate was 19 percent, and it was expected to have climbed to 30 percent in some areas by 1999 (Ministry of Health, 1999). In urban areas, the rate among those 15–49 years old was more than 28 percent; and in rural areas it was 13.6 percent (Ministry of Health, 1999). Fortunately, 81 percent of the population remains uninfected, and these people can take active measure to protect themselves.


The disease burden in Zambia is great due to HIV/AIDS. In the last 30 years, life expectancy at birth has dropped from 58 years to 37 years (Selected Socio-Economic Indicators 1998 and Living Conditions in Zambia, 1998). The infant mortality rate, at 109 per 1,000 live births, is one of the highest in the world. The maternal mortality rate of 649 per 100,000 births (DHS, 1996) is also among the highest. The under-five mortality rate is 197 per 1000. Twenty-five percent of children are undernourished, 53 percent are stunted, and 25 percent are under weight. (DHS 1996)

2.1 Morbidity Due to HIV/AIDS

An increase in the number of unusually aggressive cases of Kaposi's sarcoma was noted as early as 1983 at the University Teaching Hospital (Bayley AC. Aggressive Kaposi's Sarcoma in Zambia. *Lancet*. 1984;(8390): 1318–1320). A large proportion of Kaposi's sarcoma has also been reported among children (84 pediatric cases in 915 total reported Kaposi cases between 1980 and 1992).

Although no large studies of *Pneumocystis carinii* pneumonia have been conducted due to a lack of diagnostic facilities, the diagnosis is often made empirically (Machiels G, Uran ML. *Pneumocystis carinii* pneumonia as a cause of pneumonia in HIV infected patients in Lusaka, Zambia. *Trans R Soc Trop Med Hyg.* 1992;86:399–400). Treatment with high-dose cotrimoxazole and prednisolone has shown good results, and secondary prophylaxis with cotrimoxazole is provided (personal communication, Dr. Mwinga, include year). A recent postmortem study in children who have died from respiratory infection has shown that *P. carinii* is a common cause of mortality (ref: Kasolo,  himpi, *needs full reference, published?, personal communication?*). **Coming Monday 10/14?**

Cryptococcal meningitis is a common and, if untreated, fatal illness in individuals infected with HIV. One study reported 100 percent mortality with fluconazole monotherapy (Mwaba P, Mwansa J, et al. “Clinical presentation, natural history and cumulative death rate of 230 cases with primary cyptococcal meningitis and Zambian AIDS patients treated under local conditions.” *Postgrad Med J.* 2001;77:769–773).

Gastroenteritis is a common cause of morbidity and repeated hospital admissions among patients with HIV infection. The etiology of chronic diarrhea includes *Isospora*, microsporidians, and *Cryptosporidium* (Zulu et  *full ref. pls*). **Monday 10/15**

Oropharyngeal candidiasis is a common presentation in individuals with HIV infection and can predict the presence of CD4 counts of <200 (Hodgson A. *HIV associated oral lesions—prevalence in Zambia. Oral Dis.* 1997;May 3(Suppl 1):S46–S60). Other cutaneous manifestations of HIV include multidermatomal necrotic herpes zoster, pruritic maculopapular dermatosis, severe genital herpes, extensive molluscum contagiosum, and tinea corporis (Hira S, Wadhawan D, et al. “Cutaneous manifestations of HIV in Zambia.” *J Am Acad Derm.* 1988;(3):451–457).

2.2. Tuberculosis

Though no large-scale tuberculin survey has been performed to determine the tuberculosis (TB) annual risk of infection, it is estimated to be 2.5 percent. The case rate of TB in Zambia between 1964 and 1984 remained constant, at about 100 per 100,000 people. The case notification rate has quadrupled during the past decade. It was 512 per 100,000 people (Ministry of Health, *Tuberculosis Annual Risk Assessment, 2000*). *This is footnote reference* This increase has been largely attributed to co-infection with HIV, although undoubtedly, the decline in socioeconomic conditions in the same period has also contributed to the increase. In a study conducted in Lusaka between 1988 and 1992, the HIV seroprevalence rate in newly diagnosed cases of tuberculosis was 70 percent for all forms of TB. Higher rates were noted in individuals with extrapulmonary TB (Elliott, AM, et al.).

2.3 Sexually Transmitted Infections

Sexually transmitted infections (STIs) are an important public health problem, and their link with facilitating the transmission of HIV is well documented. The link between STIs and HIV is not well understood by many communities, and in general, the level of knowledge of STIs appears to be limited, with a strong correlation of knowledge of infections with educational status and among men. Up to 10 percent of outpatient admissions are related to STIs (Ministry of Health Analysis of the Health Sector, 2000). In 1996, 3 percent of women and 7 percent of men reported having an STI in the previous year (CSO DHS 1996). The most common infections are gonorrhea, syphilis, and cancrroids. STI infection rates are higher in urban areas than in rural areas. In 1998, 13 percent of women tested positive for syphilis during routine antenatal visits (CSO SBS 1998).

2.4 HIV Infection among Infants and Children

Transmission of HIV from mother to child is estimated to be 35–40 percent (footnote: Haya S. Kamanga J, Bhat G. et al. Perinatal Transmission of HIV.Br.Med. Journal. 1989) Babies infected with HIV in the first two years of life have a poor prognosis. Since the early 1980s, HIV/AIDS has led to a steady increase in the infant mortality rate (the number of children who die during the first year of life per 1,000 live births), and the under-five mortality rate (the number of children who die before their fifth birthday per 1,000 live births). At present, for every 1,000 children born alive, 203 die before their fifth birthday. (WHO-UNAIDS State of the Pandemic, July 2002)

HIV seroprevalance among pediatric hospital admissions has increased from 20 percent in 1992 to 35 percent in 1999. The mortality rate among HIV seropositive children in hospitals is two times higher than it is among children without HIV and who presented with similar complaints. HIV seroprevalence rates among children with TB and protein-energy malnutrition are 70 percent and 56 percent, respectively (footnote: Chintu C., Luo C, Bhat G. et al, Journal of Tropical Pediatrics). estimated 21,000 children are infected with HIV each year (MoH 1999).

2.5 Orphans In Zambia

The report, *Children on the Brink*, estimates that by 2005, 25 percent of Zambian children under age 15 will be orphans, and a large majority of them will be maternal or double orphans. Currently, most children live in a household with a surviving parent or a grandparent.

Zambia conducted a situational analysis of orphans and vulnerable children in 1999. Almost all consultant teams verified little difference between orphans and vulnerable children in their access to education, food intake, and levels of poverty. Although no national studies have been performed, small-scale studies and qualitative observations indicate that this trend is changing. Economic conditions in Zambia generally mean

biological children may receive better access to health care and education than orphan children; however, these indications have not been confirmed in a national study.

The majority of orphans and vulnerable children live below the poverty line. Small-scale studies show dramatic declines in household economic security with the death of a father. The combination of a larger number of orphans and the declining economy are quickly creating a situation in which families will be unable to care for an additional child without jeopardizing the survival of the entire family.

In addition, the emotional needs of children who grow up without the emotional support of their biological parents must be considered. It is too early to know what effect this will have on the national psyche.

CHAPTER THREE

ZAMBIA'S RESPONSE TO HIV/AIDS

Zambia has responded to the effects HIV/AIDS has had on individuals, families, and communities since the beginning of the epidemic in the mid-1980s. Since then communities, nongovernmental organizations (NGOs), the National AIDS Prevention and Control Programme (NACP), bilateral donors, the World Health Organization (WHO), and other United Nations organizations have fostered a wide variety of activities to improve HIV/AIDS care and support to people infected and affected by HIV/AIDS (PLHAs.)

The NACP was established in 1986. The first Medium-Term Plan (MTP I, 1988–1992) focused on eight areas: TB; leprosy; information, education, and communication; laboratory support; epidemiology and research; STIs and clinical care; program management; and home-based care. Support groups for people living with HIV/AIDS were established and received support, and many private sector activities were initiated.

The second Medium-Term Plan (MTP II, 1994–1998) focused on the development of a multisectoral approach. The goal was to foster continuous political commitment at the highest levels through an intersectoral committee of all ministries. The private sector, civil society, and support groups of people living with HIV/AIDS continued to play a major role. The plan also sought to increase access to STI care; control TB; strengthen condom promotion and distribution, voluntary counselling and testing, and home care; and develop strategies to mitigate the impact of AIDS (MOH TB and Leprosy AR 1996). The follow-up plan to the MTP II is the Zambia HIV/AIDS/STD/TB Strategic Framework 2001-2003 emphasizing even stronger a multisectoral responsibility and the establishment of a National AIDS Council under the Office of the Vice President.

Along with the policy work done at the MOH, initiatives have been carried out through the Central Board of Health and NGOs, supported by international agencies and cooperating partners. Through policy guidance from the MOH and technical guidance from the Central Board of Health and within the health reform framework, District Health Management Teams are now responsible for HIV activities related to the health sector. These teams form District AIDS Task Forces (DATFs), where public, NGO, and community representatives can partner to increase access to STI care; control TB; strengthen condom promotion and distribution; provide VCT, MTCT, opportunistic infection treatment, and home care; and develop strategies to mitigate the impact of AIDS. The framework for the multisectoral approach was established under the National AIDS Council (NAC) in 1999 with an interim committee. The NAC became operational at the end of 2000. The framework emphasizes the need for VCT, facility and home-based care, medication and supplies, and makes a special effort to address stigma. The NAC coordinates the activities of 14 line ministries and other actors, such as NGOs and community-based organizations (CBOs).

Many care and support approaches have been developed in Zambia, which is recognized as a pioneer in this area and a global learning site. In Zambia, HIV care and support is seen and promoted as a comprehensive package of interrelated interventions designed to meet psychological, social, spiritual, nutritional, and health needs. Comprehensive care is being promoted with a particular focus on VCT as an entry point to care, support, and prevention.

VCT services are currently being provided at more than 40 sites in all districts. As a consequence of health reform, District Health Management Teams and district AIDS task forces are promoting linkages among VCT services, medical and home-care services and social support services and support groups for PLHAs to create the provision of comprehensive care across a continuum.

The Zambia HIV/AIDS/STD/TB Strategic Framework for 2001–2003 calls for further strengthening of prevention and care and support activities. The framework identifies the following high-priority aspects of care and support.

- More VCT
- Better home-based care for people living with HIV/AIDS
- Better drug supplies
- Better hospital care
- Fewer stigmas.

The current Strategic Framework is meant to offer broad strategic guidance and policy formulation for care and support. However, it does not provide detailed guidance or standards for program planners and implementers. Moreover, it does not incorporate some important recent developments, such as therapies to prevent mother-to-child transmission of HIV and opportunistic infections, nutritional support, and safe and effective use of antiretroviral drugs. Stigma was discussed only in general terms.

In all districts, a District AIDS Task Force (DATF) has been established. Membership, often but not consistently, includes representation from the District Health Management Team (DHMT), district local government, government and mission hospitals, local health institutions, faith-based organizations, PLHA support groups, and NGOs involved in VCT and in HIV/AIDS care and support. The NHC are represented through their local health institution. DHMT takes the lead in HIV/AIDS planning and implementation of activities and services in response to the HIV/AIDS pandemic. DHMTs convene AIDS Task Force meetings for this purpose so that projects within the district fall within the objectives of the National Strategic Framework on HIV/AIDS/STD/TB; duplication of work is avoided; and plans make optimal use of scarce resources. The District Director of Health (DDH) usually chairs the DATF meetings.

3.1 Mother-to-Child Transmission

A mother-to-child transmission (MTCT) working group was established in 1999 to chart a course to stem MTCT in Zambia. The working group has developed guidelines and training modules for the implementation of MTCT services, including guidelines for

alternatives to breastfeeding. Currently, six pilot sites operate in three districts, with one urban and one rural site in each district providing zidovudine (AZT). In addition, several sites in Lusaka provide Nevirapine, as an alternative approach in a research setting. Infant feeding counselling receives special attention in one of the sites in Ndola. The MTCT working group has developed a plan to introduce MTCT services from 2002 to 2005, with the aim of expanding the service to all 72 districts in Zambia.

3.2 Tuberculosis

A national TB control program was established in 1964 after independence and was combined with the leprosy control program in 1980. As part of the second medium-term plan, the TB and Leprosy Program was integrated with the AIDS Control and Sexually Transmitted Disease (STD) Program in 1993 to form the National HIV/AIDS/STD/TB and Leprosy Program. In line with the health reform process in 1997, the vertical TB control structure was decentralized to focus on the district level. In 1998, a national TB working group was established as an advisory body to the Ministry of Health on matters of TB control. The working group forms one of the technical working groups under the NAC and Secretariat and works closely with the Central Board of Health. The current structure for TB control consists of a central unit with a TB and leprosy officer and a TB focal person in both provincial and district health offices. The current thrust of the program is to promote the implementation of directly observed treatment, short course (DOTS) using community-based organizations, community volunteers, and other treatment monitors.

In line with the World Health Organization (WHO) policy framework for the control of tuberculosis, in 1994 Zambia adopted the DOTS strategy, which focuses on passive case finding through direct smear microscopy, directly observed treatment with short course chemotherapy, an uninterrupted supply of drugs, and a system of monitoring and evaluation.

In response to the increase in TB cases in Lusaka, the Lusaka DHMT established nine new urban diagnostic centers with microscopy facilities. Research studies have been conducted in Lusaka on the role of isoniazid preventive therapy to prevent TB in individuals with HIV infection (Mwinga et al.). Various studies have also been conducted on the use of molecular biology techniques, such as DNA fingerprinting and polymerase chain reaction (Zambart report).

There are diagnostic centers in 69 of the 72 districts, and case notifications and cohort analysis are carried out quarterly. The most recent records indicate that the cure rate varies between 30 and 60 percent ([Central Board of Health Information Unit 2001](#)).

Integration of TB care into home-based care systems was initiated in the Ndola Catholic Diocese in 1995 through the Community TB Care Project, a multicenter collaborative project. This project saw the compilation and publication in 1999 of *Under the Mupundu Tree*, which describes how community volunteers play a frontline role in home care for people with HIV/AIDS and TB in Zambia's Copperbelt. In addition, many community

home-based care organizations have increasingly integrated the supervision of TB treatment into their services. In Lusaka, Chawama Interfaith and the Catholic Archdiocese provide home-based care to patients with TB. In Monze, directly observed treatment is provided through the use of relatives in a scheme based at the health center (Monze Project). Plans exist to implement directly observed treatment (DOT) in 22 districts in the 2002–2003 period.

Several studies in Zambia have looked into adherence issues among asymptomatic HIV-infected people taking a daily dose of INH for a 6-month period to prevent tuberculosis. It was found that, if a family member was supportive in supervising the daily intake, adherence was much better. These are important lessons learned as we move into easier access to antiretroviral treatment that requires lifelong daily drug intake.

3.3 Opportunistic Infections

National guidelines for the management of patients with HIV and other related complications were produced in 1993 and updated in 1996. These guidelines set out protocols for investigation and treatment of HIV-related complications for each level of health care. The guidelines were revised in 2001 and are to be published in 2002. The latest edition includes a section on the use of antiretroviral drugs for all levels of health care ([NAC Vaccine and TB TWG Report, 2001](#)).

A trial of TB preventive therapy in persons living with HIV in Zambia showed the intervention was effective in reducing the risk of tuberculosis, and the protective effect lasts more than 2.5 years ([Mwinga, et al.](#); [Quigley, et al.](#)). Currently, three sites in Lusaka (Chawama, Matero, and Chipata clinics) offer isoniazid preventive therapy in conjunction with the VCT service and MTCT service (Chipata clinic). With more sites providing voluntary counseling and testing, there are plans, through the ProTEST initiative, to increase the number of sites offering isoniazid preventive therapy as part of a package of care offered to individuals who are HIV seropositive.

Cotrimoxazole preventive therapy has been promoted as part of the minimum package of care for persons living with HIV/AIDS by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), but this intervention has not been officially adopted by the Ministry of Health. The primary reason for this is concern that the beneficial effect of cotrimoxazole observed in Côte d'Ivoire may not be achieved in Zambia due to the high rate of resistance to cotrimoxazole in Zambia. Available figures indicate that the resistance rate among hospital admissions at the University Teaching Hospital is as high as 98 percent (personal communication, Dr. Mwansa, 2002). Cotrimoxazole is widely used as a first-line drug and is provided to all health centers. Currently, three trials of cotrimoxazole are underway in Lusaka, focusing on patients with TB, postnatal women, and children. The results of these studies are expected by 2003 and will guide the Ministry of Health in deciding which policy to adopt.

3.4 Sexually Transmitted Infections

The National STI Control Programme was launched in 1981 and functioned as a vertical program based at University Teaching Hospital. The program operated through 63 specialized clinics, covering almost all district hospitals and some large health centers. Among common STIs in Zambia are curable gonorrhea, chlamydia, syphilis, and chancroid. Common noncurable viral STIs include herpes and genital warts (condylomata acuminatum). In pregnant women, syphilis is responsible for pregnancy complications such as miscarriage, premature delivery, congenital syphilis, and up to 42 percent of neonatal deaths ([Hira S, 1984. MoH](#)). Reforms were introduced in 1991 when district health boards ceased managing STIs. The Ministry of Health produced flow charts and cue cards for the management of STIs using the syndromic case management approach. Staff, mainly clinical officers and nurses in outpatient clinics, was trained in approximately 80 percent of the health centers. An assessment of STI management in health care facilities conducted in 42 health facilities in 25 districts in 2000 found a continued high prevalence of STIs and poor disease management. STI management guidelines were not always followed, and recommended drugs were not always available. Only in 10 percent of patients did health care providers score on all components of care such as appropriate diagnosis and provision of treatment according to national guidelines among those seeking care ([Zambia Health Facility Survey Report 2001, CBoH](#)).

In addition to curative management, UNICEF supported syphilis screening and treatment for pregnant mothers in five urban districts (Lusaka, Chipata, Livingston, Ndola, and Kitwe district health centers) until the mid or late 1990s. UNICEF has also supported youth-friendly services to investigate the reasons people do not seek care for STIs. Findings showed that negative staff attitudes were the greatest barrier, especially toward youth. To address this finding, a promotional campaign for youth-friendly services has been instituted, which offers youth a more conducive environment for seeking access STI to services. The private and public sectors alike have taken this challenge, and many clinics have youth-friendly corners that include peer education services. This will open opportunities to further strengthen STI and HIV prevention measures and early entry into HIV care when necessary.

3.5 HIV/AIDS Voluntary Counseling and Testing

Kara Counselling and Training Trust in 1989 initiated voluntary counselling and testing in Zambia. Other NGOs and religious organizations have since established sites and are offering this service to communities in their catchment areas.

The Zambian government, through the MOH and the COBH, embarked on establishing voluntary counselling and testing sites in all district public hospitals in January 1999. Since then, 48 sites have been established and are operational through the coordination of the Zambia VCT Services (ZVCTS), which is an arm of the MOH and the CBOH. Collaborating partners early on supported government efforts by providing test kits and funds for training activities. The ZVCTS has several roles that include responsibility for making sure that sites have adequate supplies, quality control, supervising and training of

laboratory staff, and monitoring and evaluation. Training for counsellors is done through institutions and programs recognized by the Central Board of Health. The minimum requirements set by the ZVCTS for establishing a voluntary counselling and testing site are: the presence of a laboratory or a referral laboratory, a commitment to provide voluntary counselling and testing services, services have an effect on public health, services are accessible to the public, and minimum services are replicated or offered at other voluntary counselling and testing sites under the program.

Hope Humana, a project under Development Aid People to People (DAPP) and part of the Zambia VCT Partnership, has four stations to-date providing care and support. Started in December 2000 in Livingstone, the stations support posttest clubs and counsellor support groups and encourage and expand referral networks.

3.6 People Living With HIV/AIDS

Formal initiatives to support people living with HIV/AIDS (PLHA) started in Zambia in 1991 with the Positive and Living Squad (PALS). This group of HIV-positive individuals joined together for peer support and to offer information on HIV prevention to the public. The project had several components that included training members to educate others about HIV/AIDS, and counselling and outreach methodologies. During 1992 to 1993, PALS members visited more than 850 companies and businesses and spoke to more than 85,000 people about HIV/AIDS. One of the motivations for this activity was to reach men with positive living messages, because they are less likely to have access to HIV/AIDS information. Women were also targeted with preventative messages at under-five and antenatal and postnatal clinics.

In 1992, Hope House, a center for PALS, was established as a skills training center. Training was offered in tailoring, tie and dye, and general life skills. This work pioneered the establishment of the Network of Zambian People Living with HIV/AIDS (NZP+). NZP+ support groups are composed of people living with HIV/AIDS who come together to provide HIV/AIDS education, voluntary counselling and testing promotion, positive living through behavior change, anti-AIDS clubs, and home-based care. Currently, the Network's focus is on activities that can improve the livelihood of members through partnerships with microfinance institutions, agricultural projects, and skills training. Since its inception, PALS has played a major role in advocating for proper medical and nutritional support as the key to improving quality of life. Through the Network of African People Living with HIV/AIDS (NAP+), a practical nutritional guide was produced in 1995 for people living with HIV/AIDS in Africa (Food for people living with HIV/AIDS, NAP+, Nairobi). In 1997, Hope Humana started a program for HIV+ people. The program is called "Positive Living Advocacy Course," and it is aimed at training HIV+ people to share their experiences with others. Graduates of the course are encouraged to help their communities respond to HIV/AIDS-related needs.

3.7 Community-based Care and Home-based Care

Community-based care (CBC) provides people infected and affected by HIV/AIDS with comprehensive care and, through functional referral to and from health institutions, it aims to be an essential part of the continuum of care. The objective of home-based care (HBC) is to involve communities as much as possible in providing care for HIV/AIDS patients and promoting prevention of HIV infection. Home-based care provides patients a continuum of care from nursing care, counselling, psychological support, pastoral care, social support, and other services.

To provide care for an ever-increasing number of people with HIV/AIDS, home-based care needs to be viewed as a supportive component in the continuum of care for people living with HIV/AIDS and not as a parallel initiative (Osborne et al., 1997). Meeting medical, nursing, spiritual, psychological and social needs at home within the community has been the cornerstone of the development of Home Care in Zambia since the late eighties. It allows palliation for chronic illnesses to be implemented by volunteers, community workers, and health facility staff and makes possible the necessary prevention efforts.

In Zambia, community-based care started as a result of two separate initiatives occurring almost simultaneously in 1986; the Chikankata AIDS Care and Prevention Project (From Fear to Hope – AIDS Care and Prevention at Chikankata Hospital, Zambia, 1990 and AIDS Management: An Integrated Approach, 1990), and the Churches Medical Association of Zambia (CMAZ). CMAZ is an umbrella organization of all mission hospitals in Zambia. It adopted home-based care as a viable strategy to respond to the AIDS challenge. According to CMAZ, home-based care has the following advantages.

- It uses the strengths that exist in families and communities, including the influence of the family and community on individual conduct and behavior; and the social, emotional, and physical support the family and community are able to offer to a needy member.
- It is in line with the wishes of most terminally ill patients who prefer to die at home in their familiar surroundings.
- Care of patients at home provides a basis for integrated patient care, which includes emotional, social, physical, and spiritual support, and which is often not easy to provide in a hospital setting.
- Care of patients at home provides a basis for prevention of HIV infection through health education for family members and leads to community mobilization through community counselling or dialogue.
- The care of patients at home relieves health facilities of the added burden of caring for an increasing number of AIDS patients.

A number of interventions in Zambia have been initiated to provide care to chronically ill persons within the community at their homes. The two major approaches are the institutional-based hospital outreach programs and the community-based programs often supported by churches or local NGOs. The former approach uses hospitals and health

centers and their departments or offices that offer home visit services to the chronically ill. A small number of trained health personnel receive referrals from the wards at discharge and follow up the patients in their homes at regular intervals through involvement of health center staff as well. Most of these hospital-based home care departments have a core staff of a few full-time employees, and general hospital or health center nurses receive an allowance to cover their personal expenses while they visit patients at homes in the community at regular intervals. Since 1987, Family Health Trust, a local NGO providing service to PLHA, has offered HBC through its office at the University Teaching Hospital (UTH) in Lusaka.

The community-based approach is usually initiated by a diocese or a women's or church group or a local NGO which, with the help of volunteers from within the community, visits patients at home, provides social, spiritual and emotional support, and links up with the nearby health facility when necessary. Levels of acceptance for home-based care among patients and family members are generally very high for both approaches ([Chela et al., MoH-WHO Home Care in Zambia Evaluation, 1993](#)).

A recent evaluation of the Ndola Diocese Home Care Program shows the feasibility of this approach over the past 10 years and highlights the necessary elements, such as nursing care, counselling, psychological support, pastoral care, social support, and other services. The people that carry out home-based care include nurses, spiritual staff, volunteers, and administrative staff.

In general, terminally ill patients would rather die at home (Boswell, 1999). The Chikankata AIDS Care and Prevention Project found that when a family member was hospitalized, the other family members would leave the village to be at the hospital. This causes economic disruption as family members may have to travel long distances, transport costs are high, and harvesting and planting may be delayed when the illness occurs during these periods.

The lack of sufficient facilities to provide TB care and treatment results in delay in diagnosis, drug shortages, low completion rates, high default rates, inadequate recording, little interaction with government tuberculosis programs, and inadequate training for staff. Community-based care has the potential to improve care for patients with TB, and thereby reduce the load on overwhelmed health facilities. Close interaction with the national TB Control program is paramount; hence, the merger at all levels of the AIDS and TB programs. Home-based care also has the potential to reduce the congestion at health institutions, to reduce the cost of care, and provide patients with a wide range of palliative services besides clinical care. The substantial costs in home care include drugs, counselling, and supplies. Transport costs are high to provide supportive supervision, community training, referrals, and dignified transfer of clients. Donor agencies also provide some support, such as partial operation and infrastructure costs, medicines, food, and transportation.

CHAPTER FOUR

OBJECTIVES AND METHODOLOGY

5.1 Background and Objectives

The Zambia HIV/AIDS Care and Support Assessment was carried out at the request of the National AIDS Council (NAC) through its Voluntary Counselling and Testing (VCT) and Care Technical Working Group. The purpose of the assessment was to identify the scope and capacity of the current provision of HIV care and support at sites in two rural districts (Lundazi in Eastern Province and Mongu in Western Province), and two urban districts (Ndola in Copperbelt Province and Lusaka in Lusaka Province). The four districts have a combined population of 1,900,545, or approximately 20 percent of the total population.

The Technical Working Group (TWG) asked the assessment team to research what the needs are to meet a set of minimal HIV care standards in districts known for their HIV care and support activities. The TWG committee hoped, as one of the outcomes of the study, to be able to define a standard package of HIV/AIDS care and support, relevant to district level annual planning and in accordance with the Zambia HIV/AIDS Strategic Framework 2001-2003.

In response to the request of the NAC Technical Working Group, the objectives of the assessment became to

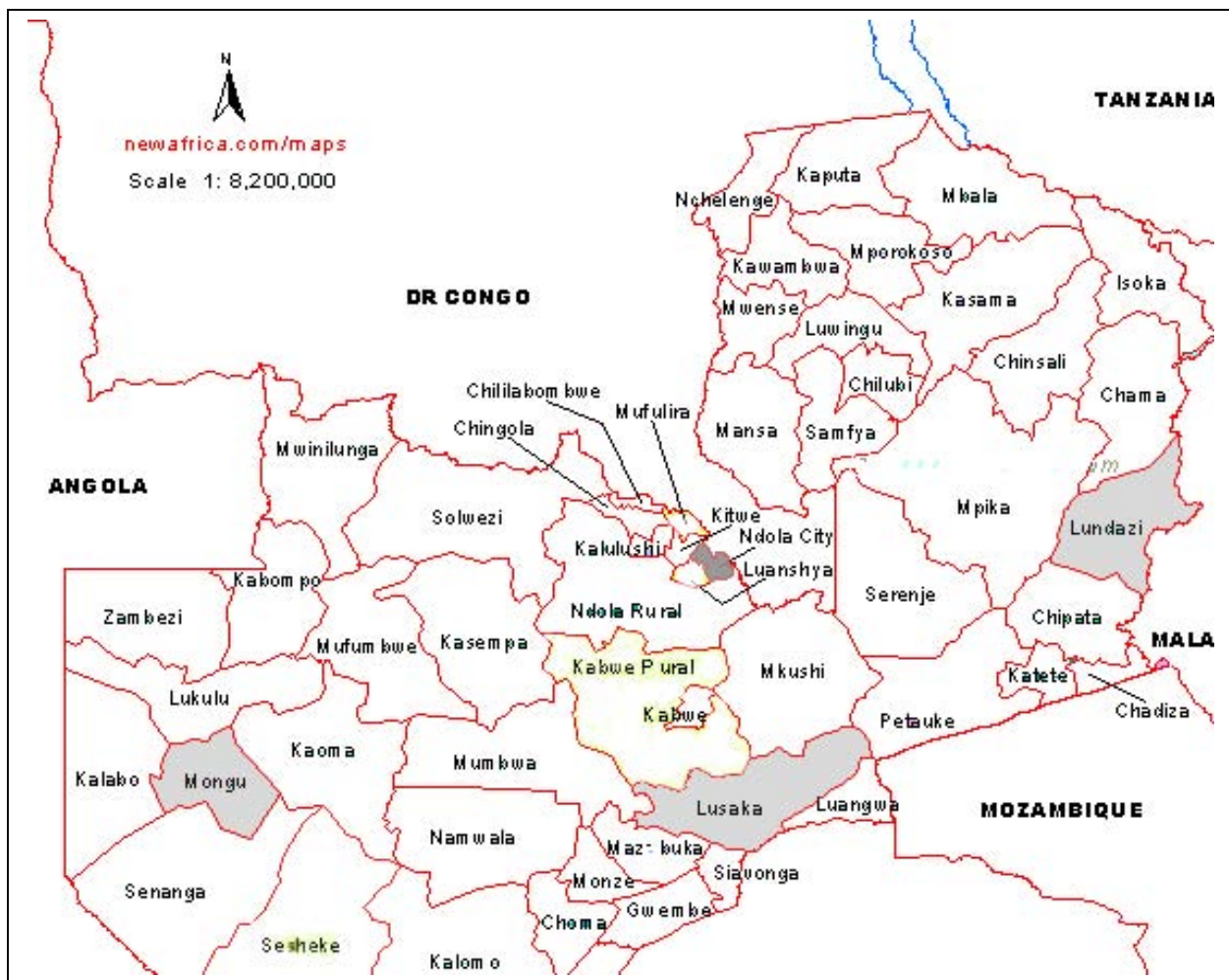
- Identify district-level opportunities and challenges in HIV comprehensive care and support to review the care and support standards, and
- Design a district-based HIV comprehensive care and support package to improve the quality of life of people living with HIV/AIDS.

The revised care and support standards and the enhanced care and support package will assist Zambia in meeting the NAC's goals as outlined in the National Strategic Framework 2001-2003.

KARA Counselling and Training Trust (KCTT) was requested to be the operational arm of the assessment, with consultation support from key members of the committee, national public health consultants, and technical support from USAID's Synergy Project/TvT Associates, and USAID's IMPACT Project/Family Health International (FHI). USAID Zambia provided the necessary funding.

5.2 Selection of Districts and Sample of HIV/AIDS Service Sites

The four districts included in the assessment were selected on the basis of the VCT and care and support activities and services provided within each district. Two urban and two rural districts were selected. Each of the four districts had sites with facilities that provided one or more HIV/AIDS care and support services. A sample of these sites were selected and included in the assessment.



Map of Zambia highlighting the four districts where the assessment was conducted

The following criteria were used in selecting a sample sites within each district where data was collected for the assessment. A sampling site was defined by the geographic catchment area of a health facility within each district. Voluntary counselling and testing and care and support services were to be available within the catchment area. There was to be variation in the type of support for institutional and community-based voluntary counseling and testing and care and support initiatives (government, NGO, and other). Other factors were the number of sites in relation to the district population and a variation in resource management and utilization. There were to be hospices, private clinics, or home-based care within the catchment area. A requirement was the possibility of conducting at least two focus group discussions with health providers, community volunteers, and people living with HIV/AIDS, and an in-depth interview with at least one person infected or affected by HIV/AIDS.

After establishing these criteria, the following steps were used to identify facilities and respondents that participated in the assessment.

1. A list of facilities in each district was developed.

2. Sampling sites were then ranked on the basis of selection criteria (for example, facilities not providing any relevant VCT and care and support service were excluded from the survey.)
3. A list was prepared by site of all health staff (nurses, doctors, clinical officers, etc.), community-based support groups, and groups of people living with HIV/AIDS.
4. Using this list, respondents and groups were selected for focus group discussions.

4.3 Selection of Respondents and HIV/AIDS Care and Support Facilities

All relevant social and economic groups expecting to benefit from increased care and support efforts were to be included in the assessment. Two factors taken into consideration were the convenience and cost implications in terms of distance and time to and from the catchment area and staff availability and time for interviews. A purposive sample of respondents was selected for the survey of health care providers. The assessment teams were directed to ensure that the sample include an adequate number of facilities to allow for analysis by districts. See Table 1 for sites selected.

Focus group discussions included persons living with HIV/AIDS, facility-based health care providers, and community-based health care providers. Where it was not possible to hold focus group discussions, they were replaced with in-depth interviews. Depending on the situation, the team manager, in consultation with the field team, decided how best to substitute focus group discussions with in-depth interviews, where appropriate, to collect representative information. A minimum of five in-depth interviews per district was expected.

4.4 Data Collection Methods

The assessment used both qualitative and quantitative data collection methods, including the participation of Zambian care and support stakeholders in the data analysis and development of a district level care and support package. Data was collected between January and March 2002.

The qualitative methods included

- A review of published and unpublished literature on HIV/AIDS care and support in Zambia;
- Focus group discussions with facility- and community-based HIV/AIDS care providers, and people living with HIV/AIDS; and
- Structured in-depth interviews with members of District Health Management Teams.

The quantitative data collection focused on a survey of HIV/AIDS care providers in the four districts, using a structured questionnaire. Enumerators recommended by the DHMT administered these questionnaires used in the quantitative data collection. District Health Management Teams were requested to recommend candidates to serve as enumerators according to specified criteria that included ninth grade education, data collection experience, availability, district residency, and multisectoral representation. The district

field teams consisted of a team manager who was a member of the core assessment team, a facilitator, a supervisor, and four enumerators

Table 1. VCT and Care and Support Assessment – Sites Participating in Focus Groups, In-depth Interviews, and the Survey of Health Care Workers

District	Health Catchment	Facilities Participating in the Assessment
Lusaka	Kabwata	University Teaching Hospital; Maina Soko Military Hospital; Kabwata Urban Health Centre; Maina Soko Military Hospital Home Based Care; UTH Home-based Care; John Hospice; KSHHV – 8 centers (ARV study)
	Chipata	Chipata Urban Health Center
	Matero	Matero Urban Health Center
	Mutendere	Mutendere Urban Health Center; Mutendere Home-based Care
	Chainama	Chainama Teaching Referral Clinic; Chainama Hills Psychiatric Hospital
	Kamwala	Kamwala Urban Health Center
	Chilenje	Chilenje Urban Health Center; Lusaka Archdiocese Home-based Care
Mongu	Limulunga	Mongu Diocese Home-based Care; Limulunga Rural Health Center
	Sefula	Reformed Church Home-based Care; Sefula Teaching Rural Center
	Namushakende	Namushakende Rural Health Center
	Mulambwa	Mongu Diocese Home Based Care
	Lewanika	Lewanika General Hospital; Lewinka General Hospital Home-based Care; Mongu Diocese Home-based Care
	Nalwei	Nalwei Rural Health Center
	Lumezi	Lumezi Mission Hospital
Lundazi	Kanyanga	Kanyanga Zonal Rural Health Center; Enusa Sub Center (Community Care)
	Lundazi Central	Lundazi District Hospital; Thandizani C.B.P.C.; Kamukule Club; CAPCOM Lutheran World Federation
	Mwase Lundazi	Mwase Lundazi Rural Health Center
Ndola	Railway	Railway Clinic; Ndola Central Hospital; Maongo Clinic; Mory Begg Memorial Clinic
	Nkwazi	Hope Humana; Kalewa Barracks Military Hospital; Nkwazi Urban Health Center; Zambia Flying Doctors; Chilshilano Home-based Care; Arthur Davidson Children's Hospital; ZESCO Clinic
	Twapia	Lubuto Urban Health Center; Chichetekolo Hospice; Chichetekolo Home-based Care
	New Masala	Mushili Urban Health Center; Kava Health Center; Mushuli Community Home-based Care; Ndola Catholic Diocese Home Based Care

All data collection instruments were field tested during a workshop held in Lusaka in January 2002. All facilitators, supervisors, and enumerators attended this workshop. Activities included revising the draft data collection instruments, piloting the data collection procedure, and finalizing the tools. The district assessment teams had prepared district population profiles and main economic activities in preparation for the workshop.

Quantitative data were collected through a questionnaire administered by enumerators, whereas qualitative information was obtained through focus group discussions and in-depth interviews using a discussion guide. All completed questionnaires were handed to

the supervisor at the end of each day for quality checking. Focus group discussions were recorded manually and tape-recorded. In addition, focus group discussion matrices were used to summarize the information. Focus group discussions were conducted by two team members (team manager, facilitator, or supervisor). Information provided by District Health Management Teams and District AIDS Task Forces were collected using a qualitative questionnaire.

Logistics and resources determine the sample and responses. Some facilities within the selected districts were inaccessible due to impassable roads and time constraints. Districts facilities and respondents were not randomly sampled; they were chosen according to the set criteria. Interviews were conducted, but there were no observation of practices. Research fatigue in urban areas was a challenge for data collection.

Three meetings were held as part of the assessment process: a data analysis review in April 2002 and a review of these findings and recommendations in July 2002 with the NAC TWG for VCT and Care and Support. The September 10, 2002 dissemination meeting of cooperating partners, NAC members, consultative members, and nongovernmental and community-based and church-affiliated representatives endorsed the final standards, district package, and national recommendations.

4.5 Review of Literature and Other Information

The collection of literature and other information was an ongoing process during the period of the assessment. In preparation for the assessment, literature outside the focused collection and review were also consulted. The Zambia search was limited to research and information that fell within the scope of the objectives. Information was collected in consultation with and assistance from the VCT and Care and Support Technical Working Group of the National AIDS Council. In addition to a search of published literature in scientific journals and conference presentations, some United Nations agencies, donors, local and international NGOs, faith-based organizations, government departments, institutions, and ministries were canvassed for information.

A wealth of pioneering documentation was collected on HBC, VCT, clinical management/TB and OVC. The collection includes published and unpublished reports, assessments, evaluations, power point presentations, service implementation guidelines, and information and education materials.

The collection of literature on Zambian VCT and care and support had the following constraints.

- Limited available or accessible information
- No central depository for information on the subject.
- The focal or lead person for an activity or service left the position without passing on reports or adequate information. In some cases, no records were kept.
- A project or initiative may have been completed or phased out without the information or literature being passed on.

4.6 Survey of Health Care Workers

A total of 545 health care providers responded to the HIV/AIDS care and support assessment survey. More than half (57 percent) of all respondents were enrolled nurses, and about a fifth were registered nurses. Medical doctors (5 percent), and social workers (1 percent) were the least represented in the sample. Of the 29 medical doctors who participated in the survey, half were from Lusaka. See Table 2: Health Care Workers by District.

Eight types of health facilities within the selected sites were included in the assessment. These included 1) referral hospitals, 2) general/district hospitals, 3) mission hospitals, 4) urban hospitals, 5) rural health centers, 6) private clinics, 7) hospices, and 8) voluntary counselling and testing facilities.

Table2. Health Care Workers by District

	Total (n=545)		Lusaka (n=289)		Mongu (n=99)		Lundazi (n=53)		Ndola (n=104)	
	#	%	#	%	#	%	#	%	#	%
Doctor	29	5	15	5	1	1	4	7	9	9
Clinical Officer	74	14	33	11	15	15	13	25	13	13
Registered Nurse	122	22	74	26	12	12	7	13	29	28
Enrolled Nurse	313	57	165	57	71	71	24	45	53	51
Social Worker	7	1	2	1	0	0	5	9	0	0
Total	545	100	289	53	99	18	53	10	104	19

In some places, few health care workers were available for interviews. Health care providers perform multiple functions as HIV/AIDS care providers within the facility. As a result, some respondents responded to questions in more than one section of the survey. Respondents occasionally interrupted the interviews to respond to health care emergencies within the facility. In rural areas, health care workers perceived participation on the study team a privilege, whereas in urban areas, it took longer to negotiate participation in the assessment because of research fatigue.

4.7 In-Depth Interview of District AIDS Task Forces

Respondents were selected from District Health Management Teams who were members of the DATF. These included the District AIDS Coordinator, District Director of Health, the Manager for Planning and Development, and representatives from NGOs and faith-based organizations active in providing care and support for people with HIV/AIDS.

Budget data were collected from the accounts department, working in conjunction with District AIDS Committees and other people who handled funds for HIV/AIDS activities within the District Health Management Team.

District budget information was not stored in the same format used in the questions posed in the tool. Generally, HIV/AIDS funding is not a separate budget item. Information is aggregated in the health management information systems at health posts and health centers, which made interpretation difficult.

Much of the information was dependent on the knowledge of a select group of people who were not always available. Respondents were generally very busy with multiple tasks, which made it difficult to conduct meetings. Meetings were held after working hours and into the night to accommodate schedules. In rural areas, calling an additional DATF meeting was not practical as it meant bringing people together from long distances and taking them away from client care.

4.8 Focus Group Discussions with Health Care Providers and People Living with HIV/AIDS

Seventy-two focus group discussions (Lundazi, 19; Lusaka, 24; Mongu, 8; and Ndola, 21) and 38 in-depth interviews (Lundazi, 12; Lusaka, 8; Mongu, 6; and Ndola, 12) were held with more than 500 health professionals, community health providers, and people living with HIV/AIDS. For each focus group, an interview guide was used. The focus group interview guide included questions on networking, VCT, care and treatment, ARVs, Stigma, and referrals for services.

In some districts, there were not enough PLWA available for interviews nor was it possible to hold focus group discussions with PLWA because they were not open about their status. Generally, in rural areas, logistics often made it difficult to hold focus group discussions. In community groups, participants tended to look to the leader to make a presentation rather than to be involved in a discussion.

4.9 Data Processing

Information from the questionnaires was entered into an epidemiological database in Lusaka under the supervision of the data manager. The information was later exported to statistical software for analysis.

Focus group discussions and in-depth interviews were analyzed using a participatory matrix summary process. The core team members who supervised the collection of qualitative data in the field met for five days to review the data and to provide a summary of the responses from the three groups interviewed. These groups were the people living with HIV/AIDS, community health providers, and institutional health providers. The tape recordings of the interviews were used as a reference. A participatory matrix methodology was used to compile the results of the data because it was the most comprehensive method for collating data in the shortest possible time. The data have been merged in the report using the interpretative summary methodology.

CHAPTER FIVE RESULTS

This section combines the findings from the in-depth interviews and focus group discussions, with the quantitative findings from the survey of health care providers. It starts with an analysis of the findings from the in-depth interviews with DATF members.

5.1 Functioning of District AIDS Task Forces (DATF)

The District AIDS Task Force in all districts studied met irregularly because meetings are not held according to a schedule but in response to special events such as World AIDS Day or annual action plans.

In all districts the DATF was perceived as an informal body with only an advisory role to DHMT for planning HIV/AIDS activities in the district and without clear supervisory roles, terms of reference, or authority. Therefore key participants, such as referral hospital representatives, often do not participate as members in the DATF. DATF members sometimes believe coordination for comprehensive care is not their responsibility but that of the district and community.

The DATF Action Plans in the four districts mention key care and support activities as priorities: for example, capacity building through support to community-based organizations, training of counselors, and scaling-up of VCT; provision of more supplies; and expansion of STI, OVC, HBC, and income generating activities (IGA) activities. It should be noted that rarely mentioned were MTCT, stigma reduction, ART, or palliative care.

It was much more difficult to gather data in all four districts on actual funding sources and expenditures on specific care and support activities. Reasons for this lack of data include the fact that account entries on medical aspects and drugs do not specify HIV-related activities as a separate category. In addition, direct bilateral-funded activities to NGOs, bypassing the DHMT, make it difficult for the DHMT to monitor the progress of these projects and their impact in the district. Consequently, lack of coordination and duplication of activities occur. It also hampers strategic planning, monitoring, and evaluation.

Coordination of and cooperation from these organizations were found to be difficult due to the lack of reporting and different accountability systems.

5.2 Activities of the DATF with Regard to HIV Care and Support

One of the key activities of the DATF is assisting the DHMT in planning and budgeting HIV/AIDS district activities. This process results in a DATF Annual Action Plan. Ad hoc arrangements for cooperation generally follow the development of this annual plan. However, there is no structured feedback mechanism from the DHMT to other DATF members on follow-up activities, which limits the coordination function of the DATF. An

exception was the urban district of Ndola, where coordination among DATF members is better structured across a continuum. Because of the informal status of the DATF, members perceive their efforts and work as diminished and diluted, and they express the reporting process does not give direct credit to their organizations.

Dissemination of information is better to institutions than to community entities, such as Neighborhood Health Committees or private clinics. National guidelines do not reach the districts in sufficient quantities for all who need to use them. All four districts perceive that DATF is not viewed as a key facilitator for further information dissemination.

DATF members in all districts mentioned the effect of the funded HIV/AIDS care and support activities are hampered by the ongoing and increasing poverty at household level, particularly in families affected by HIV/AIDS. Economic and social needs are the most urgent care for families affected by HIV/AIDS. The DATF does not address these needs.

Mapping of existing institutions or programs active in HIV/AIDS care and support is a tool used to develop a directory of services by district or neighborhood in order to facilitate referral across a continuum between various care and support providers. Except for Ndola District, this mapping is rarely formalized and not readily available. In the smaller districts there are no written directories and referrals are verbal.

It was difficult for the districts to provide detailed information on the exact sources and amounts of funding for HIV/AIDS care programs, as these are usually integrated into general health entries. Financial information was more available for urban areas than for rural areas. The only funds easily identifiable as HIV/AIDS programs were those for specific activities, such as VCT, HBC, and counseling training.

In smaller rural districts, the Director of the District Health Management Team and senior management team members seemed to have good knowledge of the budget line items and their disbursements, but it was difficult to verify the information.

To meet the needs of those infected and affected with HIV/AIDS in all four districts, the DATFs believe VCT and care and support should be expanded to address these most urgent needs: the supply of drugs and other items, home-based care, and training and retraining of counselors.

The needs of PLHAs were said to be social and economic, which are beyond HIV care provision.

5.3 Training of Health Care Workers

The overwhelming majority of respondents to the health care workers survey were nurses (80 percent), followed by clinical officers (14 percent), medical doctors (5 percent), and social workers (1 percent). With new developments constantly emerging in the area of

care and support for HIV/AIDS patients, respondents indicated they view in-service training an important avenue further enhancing their skills and knowledge.

Among all caregivers, those from Lusaka were more likely to have reported having received in-service training, with medical doctors and registered nurse forming the largest proportion of workers reporting receipt of training. Figure 1 shows that half of all those who reported receiving in-service training were from Lusaka, more than double those in Ndola.

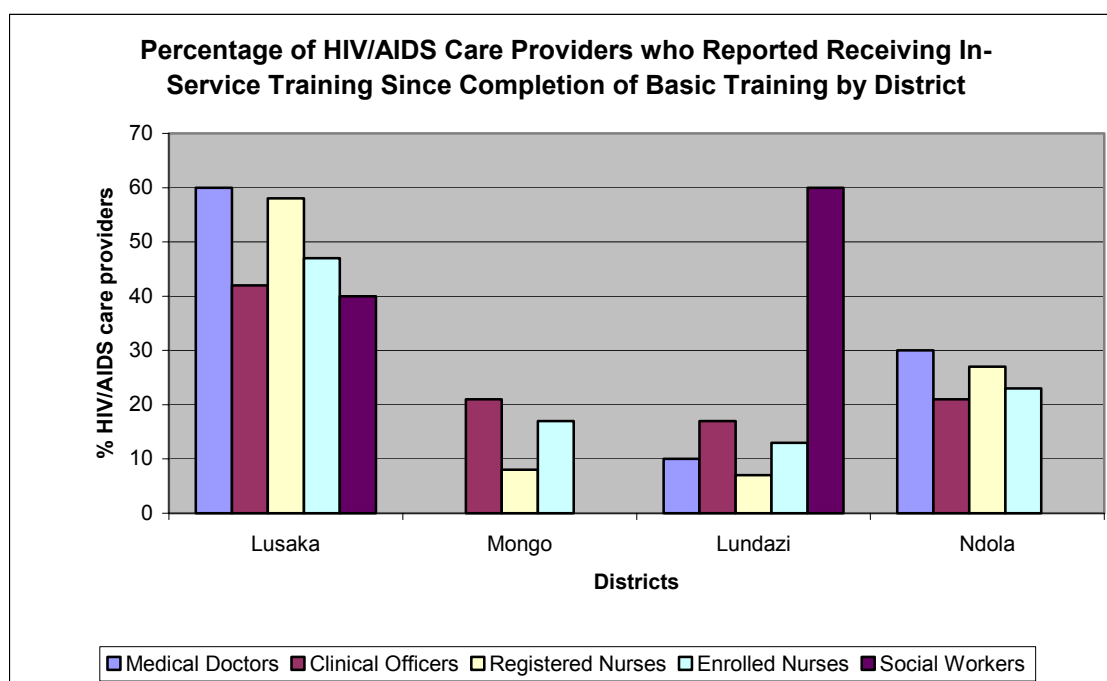


Figure 1. Percentage of HIV providers who reported receiving in-service training.

In-service training in which respondents had participated ranged from counseling training that lasted for more than two weeks (43 percent), to training in the provision of social support (12 percent), the least reported area. Other areas included clinical management (40 percent), STI syndromic management (27 percent), TB management (28 percent), and MTCT (30 percent).

Some health care providers and community members were interviewed in focus group discussions to obtain their opinions and perspectives on specific issues related to HIV/AIDS care and support activities. Several health workers said they had received training in counselling, home-based care, and AIDS management. They expressed the need for more training in counselling, particularly to meet the special needs of adolescents whose parents are infected with HIV and the need of HIV-positive individuals.

Those who had received training believed clients' needs had changed since their preservice training; they now require additional training to meet new challenges. Doctors said they had little opportunity for formal counselling training. As a result, they often write a lab request for an HIV test without discussing it with the patient because they do not know how to talk with people about the implications of testing. In a focus group discussion, doctors expressed their need for better communication skills to broach subjects related to HIV/AIDS, especially in sharing "bad news." Doctors also said "*We need training in HIV/AIDS history-taking for early diagnosis and treatment.*"

Counsellors who participated in the focus group discussions said they received generic training, but require further training in counselling interventions for specific client needs. Training opportunities listed by community members included behavior change, leadership skills, hygiene, administration of DOTS for TB, home remedies, and nutrition. Community members said the added value from the training was being able to use the information when they talked to their children. Community health providers and people living with HIV/AIDS said they need a variety of information, including how to address nutrition in HIV/AIDS-affected households.

In the September 2002 dissemination meeting, participants noted the need to include private sector service providers in training opportunities.

5.4 Clinical Care

Thirty-one percent of the 545 health care providers surveyed provide clinical care services including diagnosis and treatment of HIV-related illnesses, to HIV/AIDS patients. These providers reported they see an average 10 HIV/AIDS patients per day, including new cases and follow-up visits. Respondents in referral hospitals reported an above average caseload of 14 persons per day.

In addition to attending to patients, clinical care providers also refer patients to other clinical, counselling, and social support institutions for follow-up care and support. Sixty percent of clinical caregivers reported having referred a patient for these services in the week prior to the survey (Figure 2).

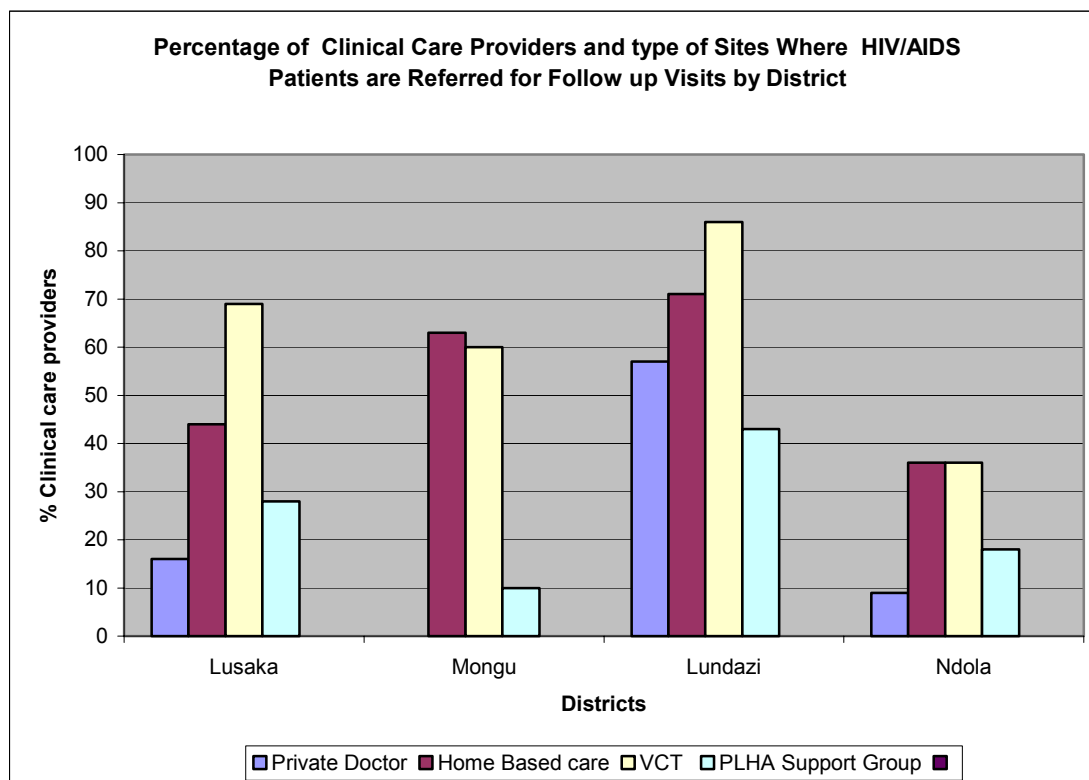


Figure 2. Percentage of Clinical Care Providers and Type of Sites where Patients are referred for follow-up Visits

More than two thirds (69 percent) of clinical HIV service providers said VCT services are provided at the facilities where they work. Respondents from rural health centers were least likely to be working at locations with VCT services: almost one-third (29 percent) of the respondents said these services were not available at their facility. Forty-three percent of respondents who provide clinical care said HIV testing is always or often offered to patients suspected of having HIV/AIDS, and 30 percent report patients always or often accept HIV testing when asked to give their consent. Fifty-one percent of respondents who provide clinical care said HIV testing is offered sometimes to patients with suspected HIV/AIDS, and 63 percent of these said patients sometimes accept HIV testing when asked to give their consent. The study took place in sites where voluntary counselling and testing were available; therefore, these figures may be high. Acceptance of VCT by patients was perceived to be sporadic, with only 30 percent of clinical providers saying testing was always accepted when offered to patients. Among parents who were offered testing for themselves or their children, only 13 percent of respondents said the offer was always accepted.

Among clinical care providers whose facilities did not provide HIV testing, 80 percent said they refer clients for testing to VCT sites, 51 percent refer to hospitals, 30 percent to health centers, and 7 percent to private clinics. See Figure 3.

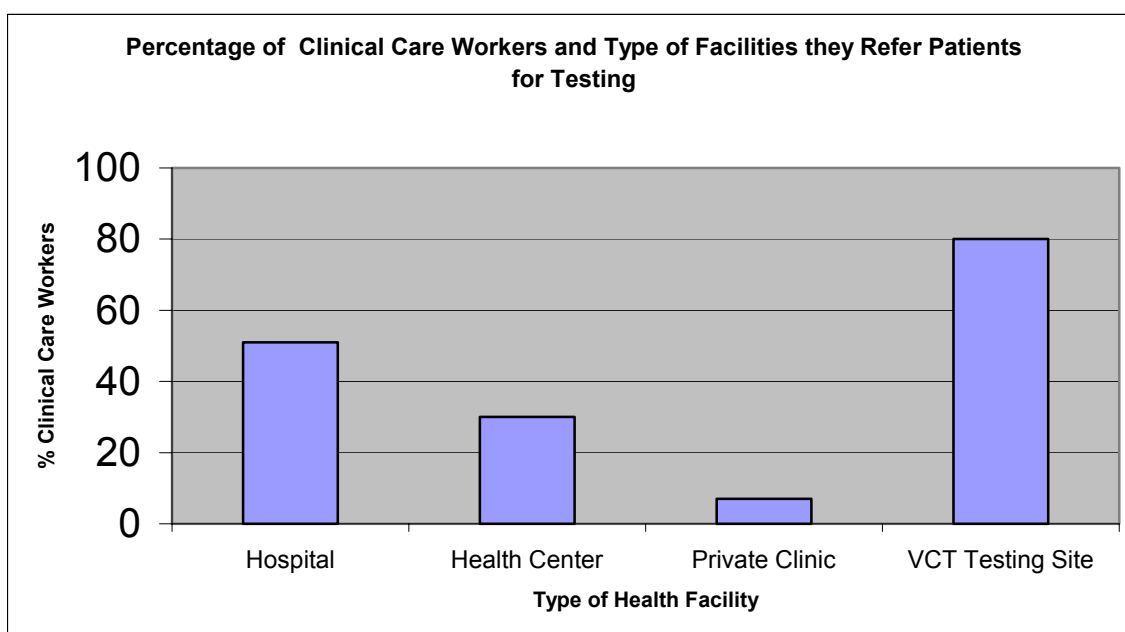


Figure 3. Percentage of clinical care providers and type of facilities to which they refer patients for testing

Antiretroviral (ARV) drugs have the potential to dramatically improve the health and extend the lives of PLHA. Among clinical HIV care providers surveyed, only 16 percent provide any form of ARV therapy to patients, compared to a much higher rate (64 percent) that provides micronutrients to patients. Treatment of children with ARVs was also limited; 12 percent of HIV clinical care providers offer ARV therapy to children with HIV/AIDS. In addition, the survey suggests training in ARV therapy offered to clinical HIV care providers is limited. More than two thirds of these workers said additional training in ARV therapy is required for them to adequately perform their job.

A large proportion of clinical care providers (73 percent) indicated they also provide palliative care as part of their job. Key areas of reported palliative care were HIV/AIDS symptom control (93 percent), medical nursing care (81 percent), and psychological support (87 percent). More than half provides spiritual support (59 percent), and psychological and spiritual support for families (54 percent). Much smaller proportions reported they provide legal support (11 percent), or assistance with writing wills (9 percent).

The World Food Programme provides high-energy protein supplements, fortified with vitamins and minerals, to patients with TB and refugees, but not to patients with HIV. In Lundazi District, it is considered a misappropriation of supplies to give high-energy protein supplementation to patients with HIV. Private businesses sell many products that could be harmful.

In the four districts covered by the assessment, 41 percent of clinical care workers in Ndola, 25 percent in Lusaka, 17 percent in Lundazi, and 12 percent in Mongu reported they provide TB preventive therapy to patients (Figure 4).

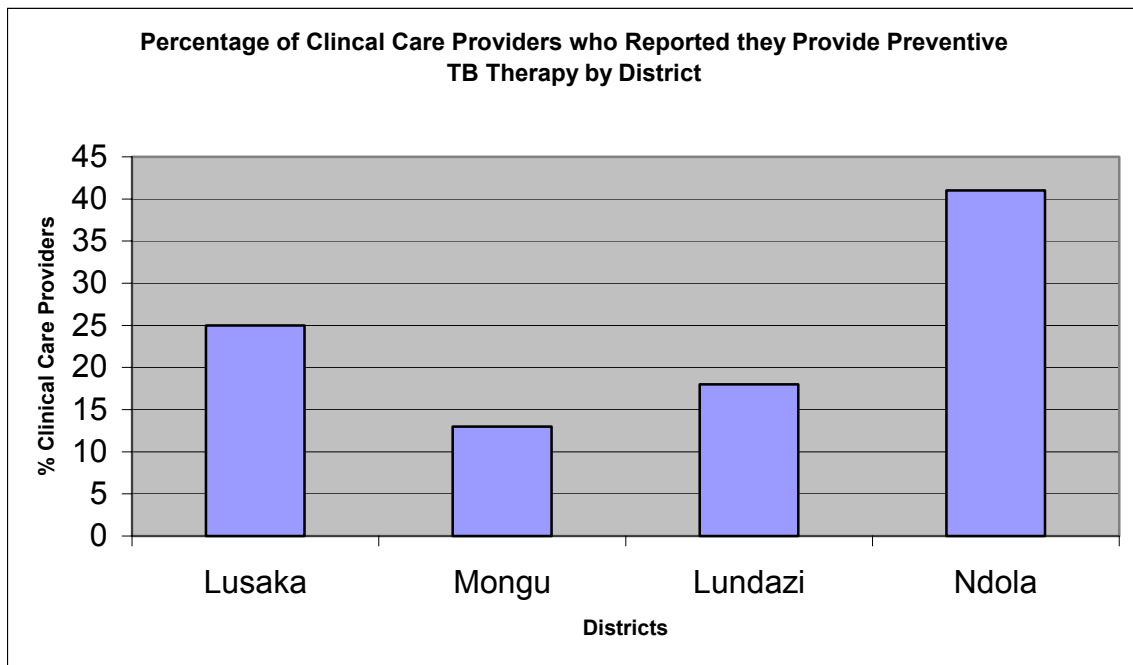


Figure 4. Percentage of clinical care providers, by district, who reported they provide preventive TB therapy.

Seventy-four percent of clinical care providers said they need additional training in providing antiretroviral drug services, 59 percent said they need more training in prophylactic treatment of opportunistic infections, 52 percent said they need better training in HIV/AIDS diagnosis, 46 percent need training in TB preventive therapy, and 44 percent need better training to distribute micronutrients. Other training needs included infections (43 percent), blood handling (39 percent), and psychosocial counselling (16 percent). More than one half of clinicians reported they need more training in the clinical aspects of HIV.

There are many guidelines available at facilities where clinicians work, although not sufficiently to make them commonly available. At VCT facilities, the counselling guideline was always reported to be available. In hospitals and health centers less than half of clinicians reported counselling guidelines were available. Clinical and TB guides are reported to be available by less than half the clinicians throughout all facilities.

5.5 Nursing Care

Out of 545 health care providers interviewed 67 percent (367) reported personally providing nursing care for patients with HIV/AIDS. Of these, registered nurse midwives and enrolled nurse midwives account for 31 percent and 65 percent, respectively. Nurses make up the largest proportion of health care workers included in the survey. Slightly more than half (56 percent) of the nurses said they had adequate training to provide services to PLHA.

The survey suggests that like other health care workers who provide care and support services, nursing training rarely covers counselling. Only 30 percent of those who provide nursing care said they received training in psychosocial counselling, and 29 percent had received training in pretest and posttest counselling. As a result, more than two thirds of nurses indicated that, for them to effectively perform their job, additional training would be required in pretest and posttest counselling, follow-up counselling, and home-based care.

The results of this assessment indicate that nurses in Lundazi (75 percent) were more likely to have received in-service training. In Ndola, Lusaka, and Mongu, nurses reported more in-service training. Also, 56 percent of enrolled nurses who responded from Lundazi, said they had received counselling training for more than two weeks. In Lusaka, 53 percent of nurse reported they had had more than two weeks of in-service training in counselling.

In focus group discussions, several nurses reported providing home-based care. By doing so, they receive favorable shifts, allowances, access to workshops, and other benefits. A program manager reported that nurses would provide care to clients outside their catchment area to receive allowances. During these discussions, the nurses also confirmed the lack of training in counselling skills; many had not received training in 15 to 20 years.

Table 3. Further Training Needs Identified by Nurses

	Total (352)		Registered Nurse (n=112)		Enrolled Registered Nurse (n=240)	
	#	%	#	%	#	%
General nursing care	122	35	36	32	86	36
Palliation	164	47	43	38	121	50
Home-based care	239	68	63	56	176	73
Follow-up counselling	240	68	66	59	174	72
Handling of blood/blood products	124	35	31	28	93	39
Nutrition	122	35	32	29	90	38

Slightly more than half (57 percent) the respondents who provide nursing care believe they received adequate training to provide care for people living with HIV/AIDS. Table 3 shows that more than two thirds of all respondents believe they need additional training

in pretest and posttest counselling (77 percent), follow-up counselling (68 percent), and home-based care (68 percent). This demonstrates a potential need for training in critical care and support areas for these workers. It is also noteworthy that nurses consider home care as an option for their patients.

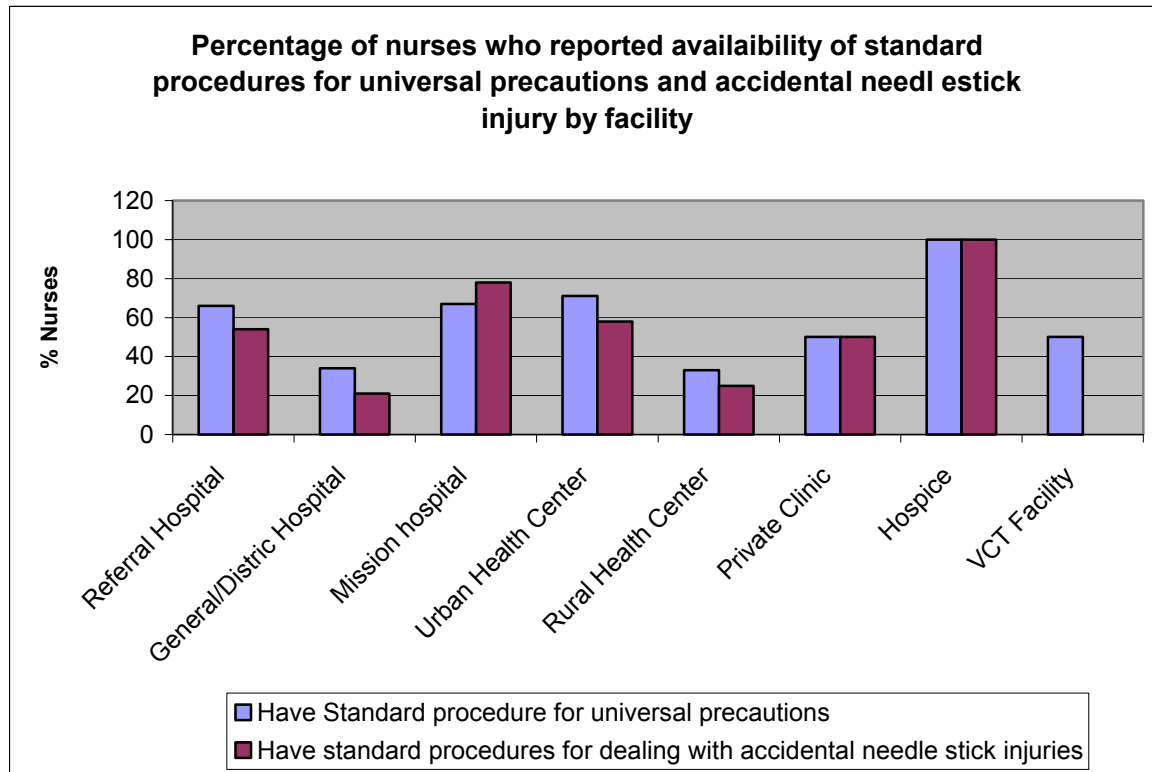


Figure 5: Percentage of nurses who reported availability of standard procedures for universal precautions and accidental needle-stick injury by facility.

Sixty-one percent of respondents who personally provide nursing care for HIV/AIDS patients reported their facility uses standard universal precautions, and 49 percent reported their facility has standard procedures for accidental needle-stick injuries (Figure 5).

Nurses in focus group discussions also indicated that they provided TB care for home-based care patients, or in a hospice or a health institution. Other services offered include offering palliative care and VCT; forming posttest clubs; offering spiritual counselling; giving medication; providing food; washing patients; and distributing condoms, information, education, and communications aimed at stigma reduction

5.6 Tuberculosis Care

Of all health care providers interviewed, 51 percent reported providing TB care; most of these worked in referral and general hospitals (58 percent and 57 percent, respectively).

Mission hospitals reported the lowest percentage (22 percent) of the workers providing TB care.

As TB is such a common opportunistic infection of HIV with serious health consequences, aspects of both [meaning both HIV and TB?] need to be closely coordinated and integrated. In the survey of HIV care providers, a little more than half of respondents reported they provide TB care.

More than two thirds of respondents in referral hospitals, general hospitals, urban health centers, and VCT centers reported that in recent years, they have witnessed a sharp increase in the number of TB patients in their facilities, reflecting the national increase of reported TB cases.

TB care providers (57 percent) in Lundazi were more likely to routinely provide VCT for HIV to patients. One-third of those in Lusaka and Mongu also reported they routinely provide VCT to their patients, and 41 percent in Ndola also reported they routinely offer this service (Figure 6.). Except for Lundazi, the majority of TB clinicians do not believe it is their job to provide counselling and testing. This sentiment correlates with the focus group discussions among clinicians, who indicated a great need for counselling and training in breaking bad news. They said, “We don’t know how to talk to people about the implications of testing.”

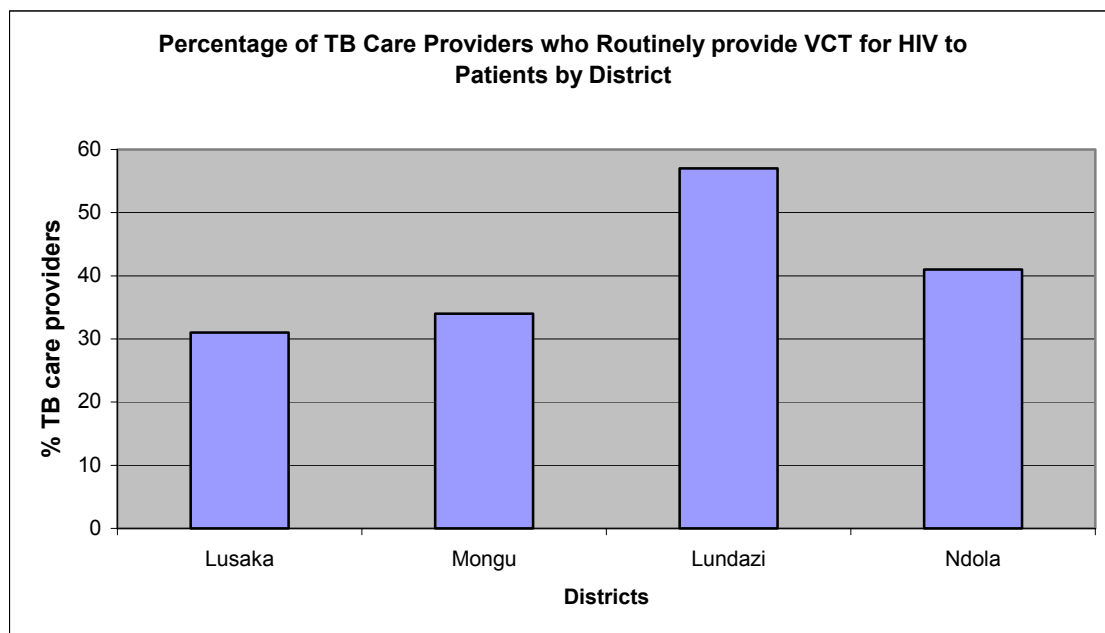


Figure 6. Percentage of TB care providers, by district, who routinely offer VCT for HIV to patient.

Drugs for treating HIV/AIDS/TB patients are not readily available in several of the health facilities. Eighty percent of HIV care providers who provide TB care said they never provide TB prophylaxis; 12 percent said they sometimes do, and 4 percent said they

always make prophylaxis available to patients. According to 60 percent of clinical care workers surveyed, insufficient drugs and lack of training and policy guidelines are the primary reasons TB prophylaxes are not provided to HIV/AIDS/TB-infected patients.

Directly Observed Treatment, Short-Course (DOTS), a WHO-recommended strategy for cure and control of TB, is used by health care facilities in Zambia (Figure 7.) It combines five elements, which include political commitment, microscopy services, drug supplies, surveillance and monitoring systems, and use of highly efficacious regimes with direct observation of treatment. The survey suggests that in Zambia, health facilities that offer DOTS usually collaborate with other programs for implementation at the community level.

Results show 39 percent of health care workers who provide TB care say they work with other organizations to implement DOTS. The general hospital workers (68 percent) collaborate most with other organizations. Seventy-nine percent of health care workers who provide TB care and work with other organizations to implement DOTS reported working with home-based care programs. Twenty-two percent said they work with community health centers, churches, women's groups, and their local District Health Management Team. No TB care workers collaborate with private companies to implement DOTS, whereas two percent of health care workers said they work with private clinics in implementing DOTS, and 20 percent said they work with NGOs.

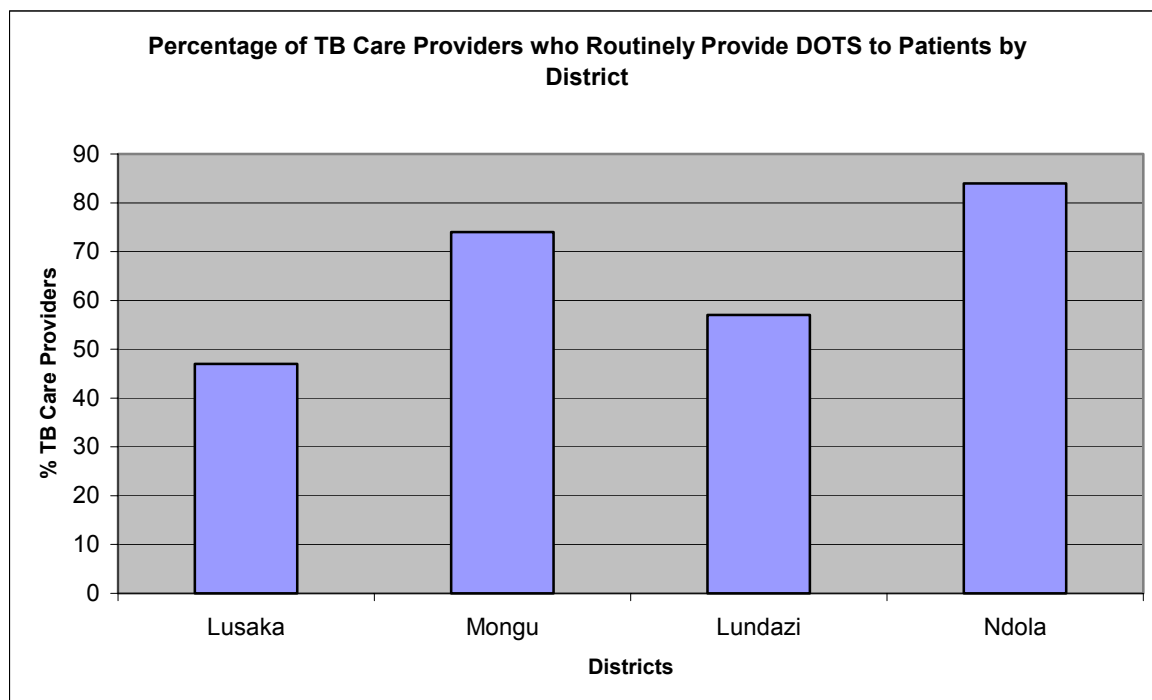


Figure 7. TB care providers, by district, who routinely provide DOTS to patients.

The majority of respondents who provide TB care in Ndola (84 percent) and Mongu (74 percent) routinely provide DOTS to patients. In Lundazi (57 percent) more than half

provided this service; in Lusaka 47 percent say they routinely provide DOTS. It is striking that a large proportion of TB clinicians in all districts do not provide DOTS as part of their responsibility. While in all districts adherence to TB treatment is mentioned as a problem, 35 percent of the providers mentioned that patients always have problems with adherence.

Reasons for patients not taking drugs as instructed include patients being too sick to take the drugs, irregular drug supply, stigma, belief that DOTS does not work properly, poor tracing, and patient inability to afford transportation to a pharmacy or clinic to obtain drugs. Other reasons offered included lack of health education and drug reactions.

During focus group discussions, people living with HIV/AIDS, health providers, and community care providers indicated they provide TB care for home-based care patients, or in a hospice or a health institution. Services include palliative care; voluntary counselling and testing; posttest club formation; spiritual counselling; giving medication; providing food; washing patients; distributing condoms; and providing information, education, and communications aimed at stigma reduction.

During focus group discussions, health providers and community care providers indicated they had some form of training in TB care. Training included counselling, HIV/AIDS documentation, use of natural remedies, and home-based care. In survey sites where community volunteers provide DOTS as part of home-based care and observation at health facilities, respondents said they had received specific training to carry out tasks related to this therapy. Seventy-four percent thought their training had been adequate.

5.7 Prevention of Mother-to-Child Transmission (PMTCT)

Mother-to-child transmission is the primary route of HIV infection in children, and programs to reduce transmission have started as pilot projects throughout the country during the past three years. Eleven percent of the 545 survey respondents said they provide MTCT care and support services. Training in the provision of MTCT care was relatively high among respondents who provide these services, with 75 percent of those who provide MTCT care and support reporting they received an average of three weeks of training in counseling to prevent MTCT. The most common services reported were, infant feeding counselling (74 percent) and pre- and post-VCT counselling (66 percent). Less than half provide assistance with feeding formula (44 percent), ARV therapy (42 percent), or referral to other community services (42 percent).

Providers in all districts reported provision of pre/post test VCT as their main MTCT activity. More than two thirds of respondents from Lusaka (77 percent) and Lundazi (75 percent) reported they provide this service. Slightly more than -half (52 percent) of respondents from Ndola also say they provide VCT to patients, and less than half of those in Mongu (40 percent) provide pre/post test VCT. Other activities mentioned were infant feeding counselling and the provision of referrals.

Of the pregnant women offered voluntary counselling and testing services, 8 percent always accept it, 77 percent sometimes accept it, and only 2 percent almost never or never accept it. In addition, 89 percent of caregivers say they allow partners of pregnant women to participate in voluntary counselling and testing. Seventy-seven percent of respondents say partners sometimes take part in the service, whereas 9 percent of partners are likely to always accept the service.

ARVs have also been found to be effective in reducing the risk of HIV transmission between mothers and their babies. Among respondents who reported they personally provide PMTCT services, only those in Lusaka (77 percent) and Ndola (12 percent) reported they provide antiretroviral drugs to their patients, as the pilot MTCT sites in these two districts include these drugs. Respondents from referral hospitals (44 percent) and urban health centers (55 percent) indicated ARVs are available at their facilities for treating pregnant women. For these respondents, ARVs were primarily available as part of a special HIV/AIDS project, not through the regular drug supply.

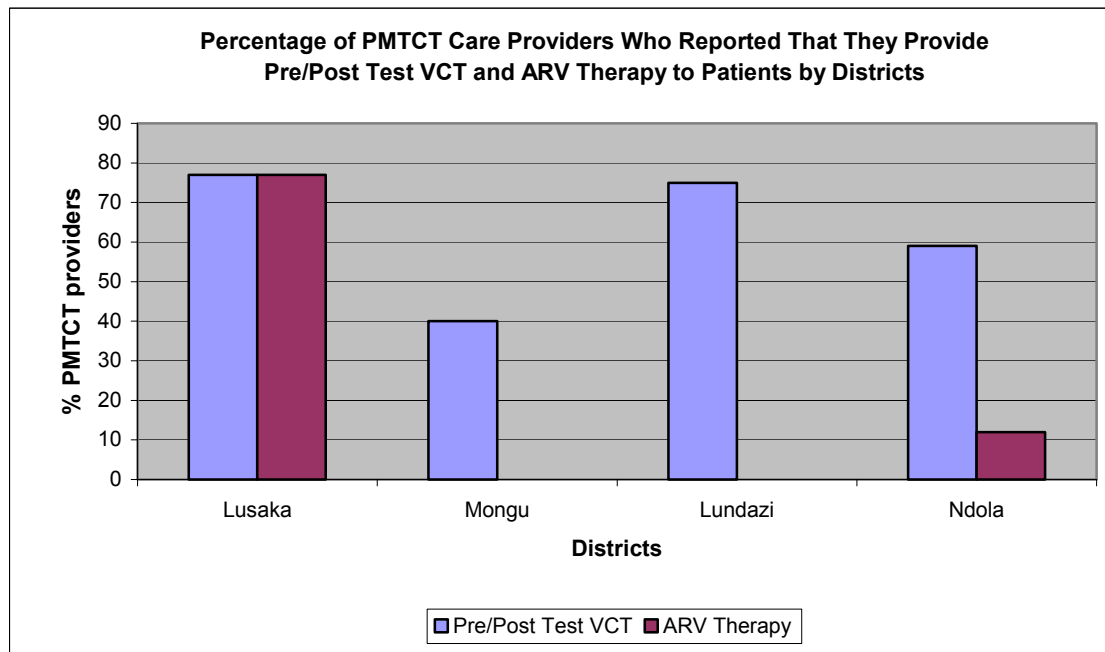


Figure 8. Percentage of PMTCT care providers, by district, who reported they offer pre/post test VCT and ARV therapy to patients.

Expansion of MTCT care has great potential to reduce the number of children who might be infected with HIV via their mothers, as well as to increase opportunities for care and support of pregnant women and mothers infected with HIV/AIDS. More than half of all survey respondents who provide MTCT care and support identified the following (figure 9) as the main obstacles to improving and expanding MTCT services: staff shortage (66 percent), equipment shortage (60 percent), and stigma (57 percent).

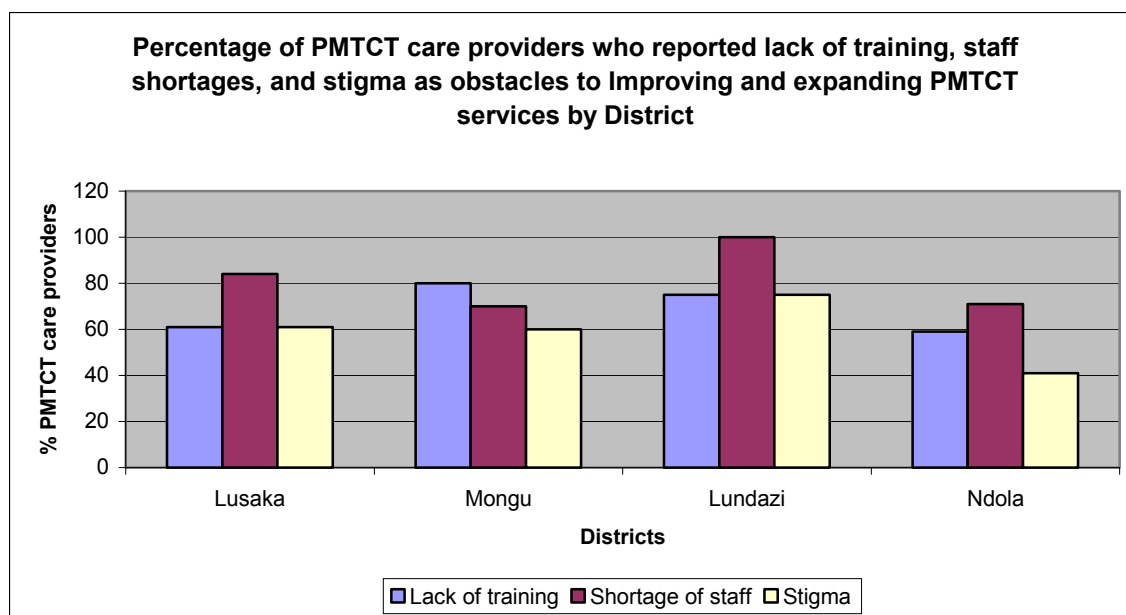


Figure 9. Percentage of PMTCT care providers who reported lack of training, staff shortages, and stigma as obstacles to improving and expanding PMTCT services by district.

In Mongu, lack of training was cited as the most significant obstacle to expanding PMTCT services. In Lundazi (75 percent), Lusaka (61 percent), and Ndola (60 percent), stigma was also cited as an obstacle to expansion of PMTCT services. These results were confirmed in focus group discussions with care providers and community members. Another important problem revealed at these discussions was the lack of MTCT information at community levels on the effectiveness of current interventions to reduce MTCT. Knowledge levels, however, were higher in the catchment areas of the specific pilot studies on MTCT in Lusaka and Ndola. Many respondents expressed community stigma against women returning home from the antenatal clinic (ANC) with formula supplies, which was mistakenly perceived as carrying HIV treatment.

Focus groups participants said an important obstacle was the lack of mother-to-child transmission information within the community, and that most people do not understand how transmission of HIV could take place between mother and child. Health workers reported better knowledge in communities where these services were promoted and available. In one survey site where services are available, confidentiality and stigma were reported as barriers to using the service because everyone in the community ‘could tell’ if the mother was positive when they carried the food supplements in a bag at the end of the clinic session.

5.8 Counseling

One in five health care workers surveyed reported they provide counselling services to HIV/AIDS patients. A large proportion (86 percent) of those who provide counselling indicated these services are formally recognized in the health facilities where they work.

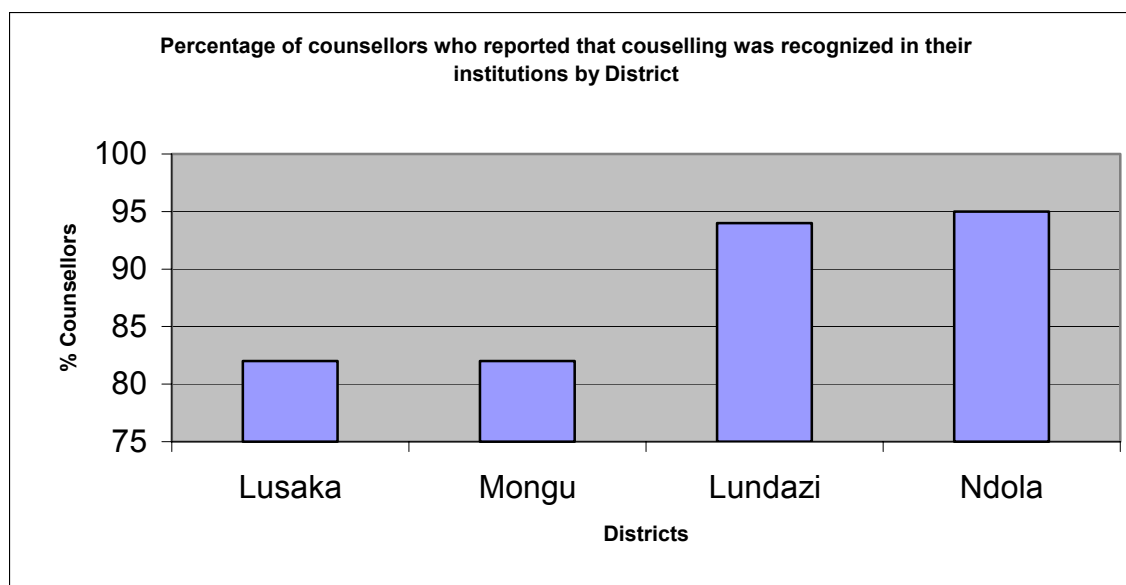


Figure 10. Percentage of counsellors who reported that counselling was recognized in their institutions by District

Health care workers indicated that more training would be required for them to adequately counsel patients. Among those who provide counselling, 39 percent reported they had received in-service training in counselling for more than two weeks, suggesting that the majority provide counselling without adequate training.

A private space is provided for counselling patients within most health facilities. Most respondents (68 percent) indicated that counselling takes place in a special room in the facility. Counsellors reported they spend an average 28 hours a week advising HIV/AIDS patients, and see an average 12 clients per week. Two respondents from referral hospitals and urban health centers reported a higher counselling caseload with each seeing 15 and 14 people per week, respectively.

Almost two thirds of respondents who provide counselling services reported they also provide services after their regular working hours. Workers from general district hospitals (92 percent) and VCT facilities (83 percent) were more likely to report they provide services outside of their normal work schedule. These workers devote an estimated 5 hours a week of their private time counselling HIV/AIDS patients.

Group counselling (defined as pretest information sessions) was reported as a method used by respondents who provide counselling services. Respondents from Lundazi (61 percent) and Lusaka (56 percent) were more likely to report using this approach (figure 11). Less than half of the counsellors in Mongu (41 percent) and Ndola (38 percent) say they use group therapy. In general, it shows the increasing popularity among counselors for group pretest counselling.

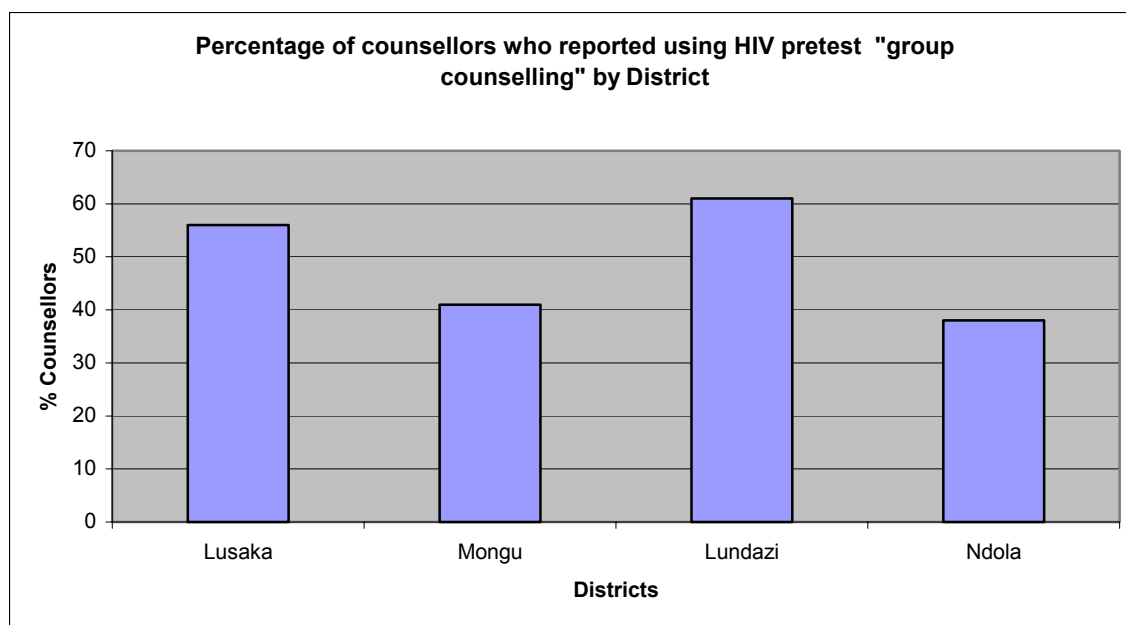


Figure 11. Percentage of counsellors who reported using HIV pretest "group counselling" by District

Even though couples counselling reduces the risk of couples having unprotected sex with their spouses, especially in the case of discordant partners, the survey suggests recommending group counseling to patients is not standard practice. Only 9 percent of respondents said they "always" recommend counselling for couples, while the vast majority (77 percent) said they "sometimes" recommend couples counselling. The advent of the availability of ARV also offers special counselling challenges in providing services to couples.

During counselling sessions, the following topics are discussed with patients: HIV risk reduction and condom use (96 percent), STIs (91 percent), family planning (77 percent), and partner notification (77 percent). Half to slightly more than half of respondents who provide counselling say that they also discuss PLHA support (50 percent), and infant illness (55 percent). Domestic violence and adherence to drugs are discussed by less than half of the counselling service providers.

Respondents who provided counselling indicated a wide variety of reasons patients visit them for counselling. According to 73 percent of the health care workers who provide these services, patients seek counselling because they want to know their HIV status or suspect that they are infected (61 percent). In Ndola (95 percent) and Lundazi (89 percent), wanting to know HIV status was the reason provided by a majority of the respondents. This reason was followed by: wanting to marry or suspicion of being ill. In Lusaka and Mongu, wanting to know HIV status and being referred were equally important reasons. Factors related to illness or worries about behavior all play a role. Counsellors are receiving referrals from medical and nonmedical sources, suggesting the "normalization" of VCT in all districts.

In all four districts, clinicians are the most common source of referrals to counsellors (figure 12). In Mongu, 86 percent of those who provide counselling services reported they had been referred patients by clinicians. It was also the most frequent source reported by counsellors in Lusaka (79 percent), Ndola (75 percent), and Lundazi (47 percent). This indicates the significance of having trained counsellors within the district health system. It also suggests that clinicians are not doing counselling themselves, but rather referring clients to a trained professional counsellor.

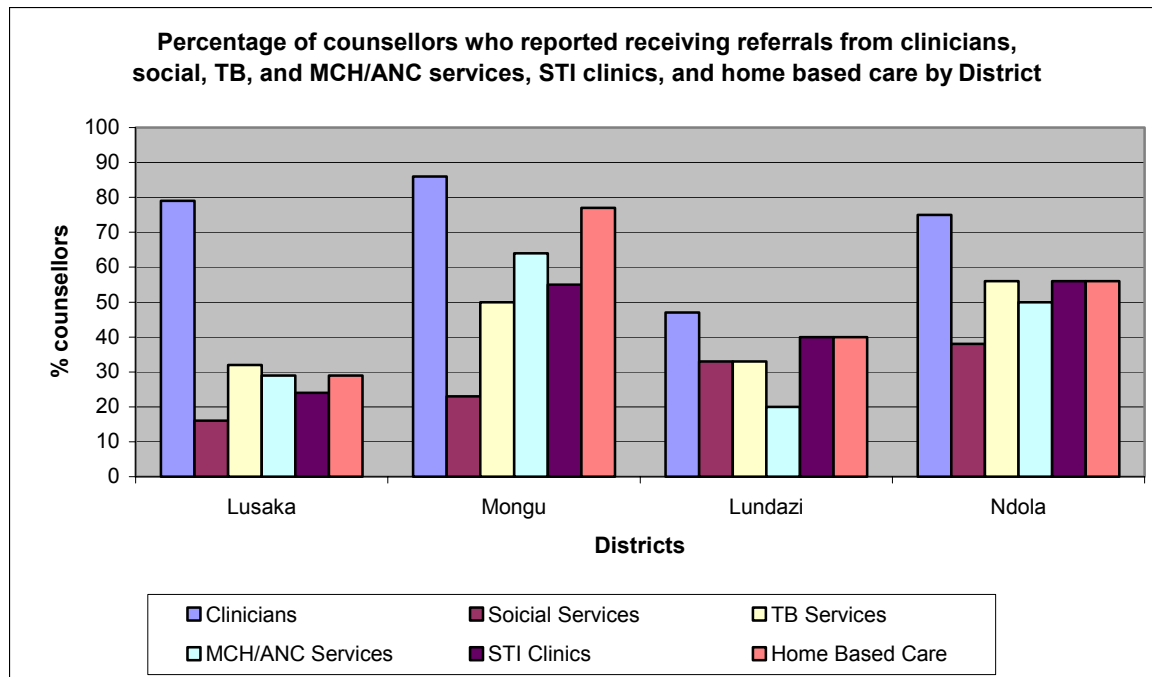


Figure 12. Percentage of counsellors who reported receiving referrals from clinicians, social, TB, and MCH/ANC services, STI clinics, and home based care by District

Sixty-three percent of counsellors refer their clients to other counsellors, 57 percent refer their clients to clinicians, and 42 percent refer clients to home-based care for TB services. Counsellors seldom send clients to traditional healers, MTCT service providers, or a referral hospital, and never to a hospice. Other clients are sent to clinics that provide care for mother and child health, antenatal care, and care for sexually transmitted infections. Clients may be sent to religious groups, social services, and support groups for people living with HIV/AIDS. In the focus group discussions, respondents expressed the “*need for referrals between counsellors and clinicians and feedback.*”

The focus group discussions with care providers also indicated a wide variety of reasons clients sought counseling (figure 13): from illness-related to “want to know” to plan for the future. Community HIV caregivers mentioned they often refer community members to VCT services. Resistance to getting tested was mentioned as quite common, with such

reasons as fear of rejection, fear of early death, lack of trust in confidentiality, and poor accessibility of sites.

Focus group discussions revealed counsellors work much the same as those who provide home-based care, providing counselling on a part-time basis outside their regular working hours. They often receive an allowance for the clients they serve under the auspices of the voluntary counselling and testing services at their facility. PLHAs in focus group discussions mentioned satisfaction with the current counselling services.

Counselling for special needs groups such as adolescents and couples is not readily available. Health workers said they have had little training in providing support and counselling for special-needs groups. They said no information exists on special needs groups. As most workers felt unable to offer their clients information on options that will provide a continuum of care, they requested training on issues related to social support.

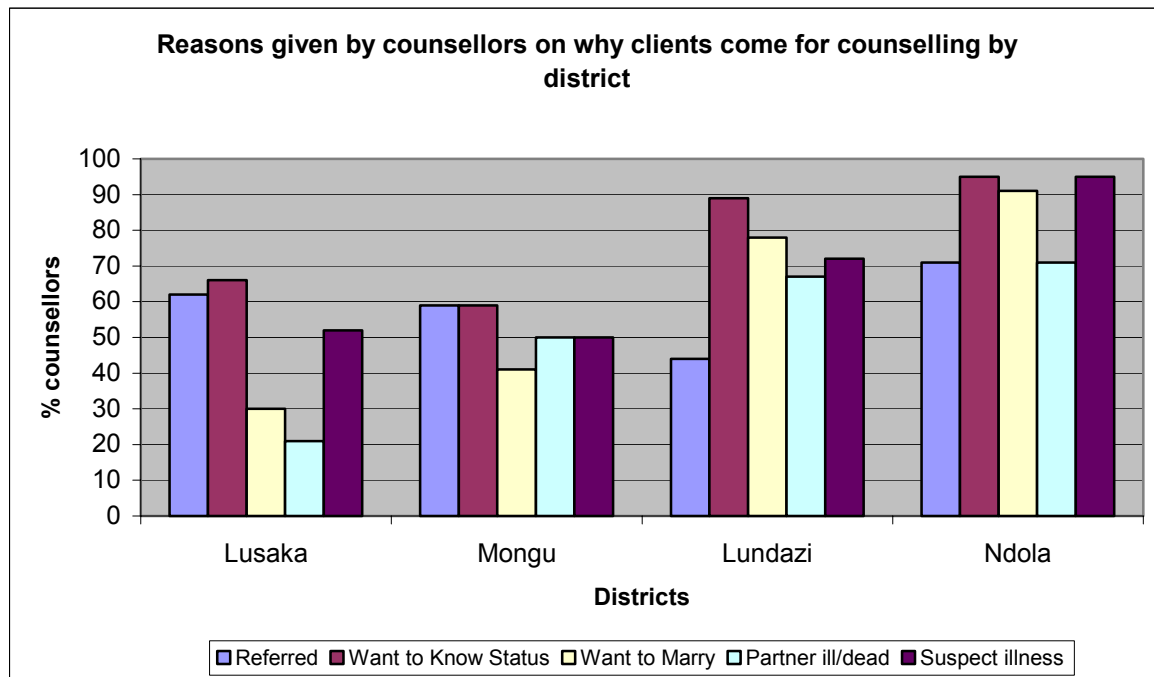


Figure 13. Reasons given by counsellors on why clients come for counselling by district

Almost two thirds (64 percent) of counselling service providers described their role as “stressful.” However, very few facilities (30 percent reported) have systems in place to deal with stress.

5.9 Home-based Care

Home-based care (HBC) for HIV/AIDS patients has been pioneered and expanded in Zambia during the past 15 years. Hospital units often initiated home-based care as an outreach service, but more and more, community initiatives have evolved. Twelve

percent of facility-based health care workers surveyed reported they provide home-based care services to HIV/AIDS patients.

A large proportion (77 percent) of home-based care providers say the services they provide were initiated by the community, compared to 16 percent of providers whose services were initiated by a health facility. Provision of home-based care services is a fairly recent phenomenon for these health care workers. They have been providing home-based care for an average 3 years. Eighty-four percent have provided home-based care for less than 5 years. Home-based care services provided by these respondents is done as part-time work (74 percent), or as unpaid volunteer work (52 percent).

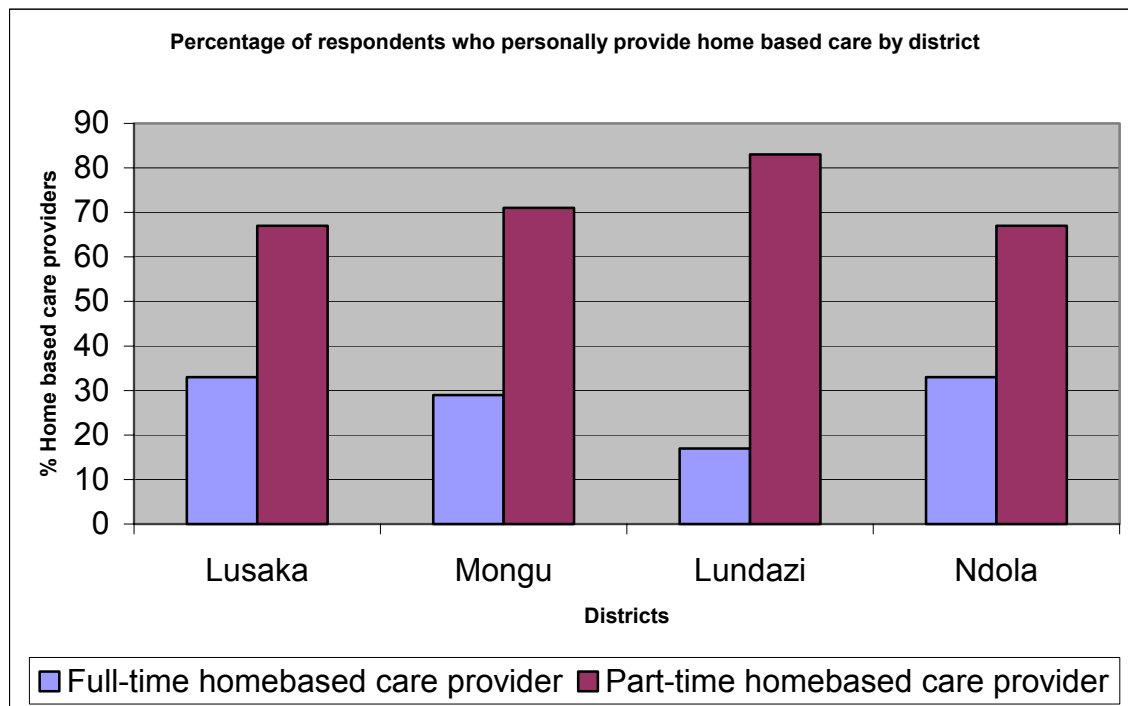


Figure 14. Percentage of respondents who personally provide home based care by district

- In general, a large proportion of home-based care providers provide part-time home care often outside working hours enabling them to earn additional financial allowances

Focus group discussions examined the distinction between full-time employment and volunteer work. When health providers are assigned duties in home care all or part of their employment duties, this work is considered employment. When health providers are employed full time for other duties, but “volunteers” to do home care on their time away from work, this is considered part-time or volunteer work. For work outside official duties, workers receive an allowance or incentive to cover the costs they incur. Many employed health workers, especially student nurses, said they do this work to augment their meager salaries. When a respondent recorded many home visits, it could indicate the person has nights off or they are on official leave from their regular duties and are working long hours in home care to earn additional income.

Across all four districts, more than two thirds of facility-based home-care providers do volunteer home care service part time?. Providers from Lundazi (83 percent) were more likely to report they provide home-based care as part-time workers (figure 14).

Enrolled nurses are the largest group (69 percent) of home-based caregivers. More than half (58 percent) of them are paid, whereas 41 percent do it as volunteers. Interpretation of these results should be done with caution, as there are few home-care providers.

On average, home-based care workers reported they provide services to more than five clients in the community per day. In all four districts home care providers give care to many clients per day. Half of those in Lusaka, and 46 percent of those in Mongu provide care to more than 10 clients daily. In the focus group discussions, home-based care providers say the same client usually is visited weekly or biweekly, except during serious illness, when clients can be visited even up to twice daily. The figures (figure 15) show, however, that with such a high caseload per home-based care provider, quality time spent with clients could be low.

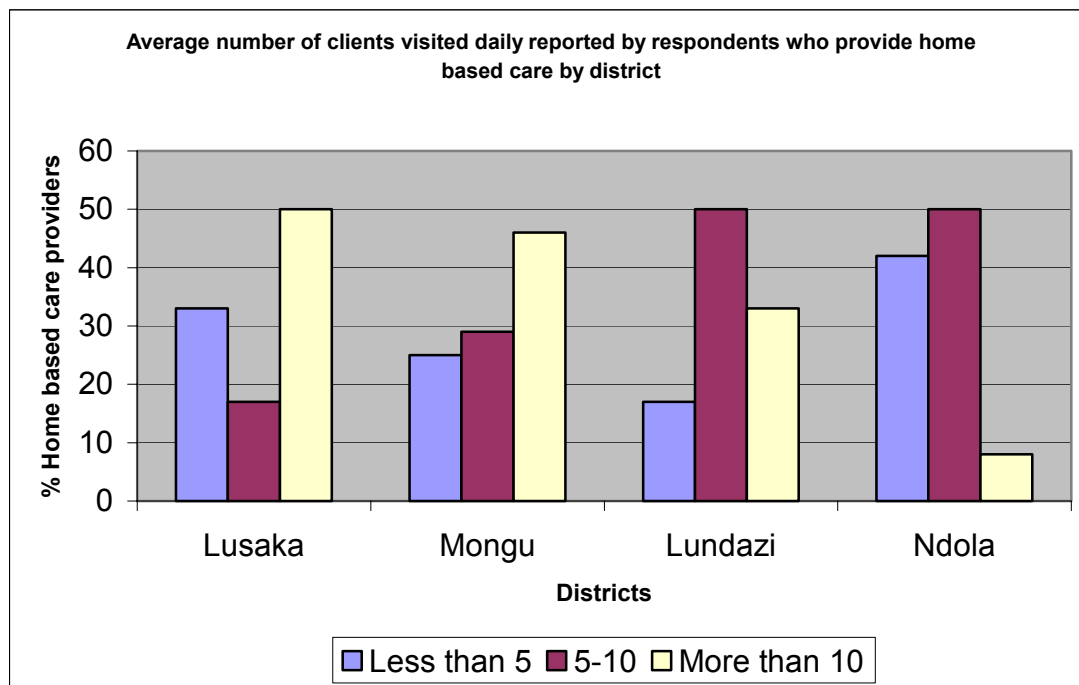


Figure 15. Average number of clients visited daily reported by respondents who provide home based care by district

Seventy-seven percent of home care providers (49 of 64) said they maintain a register that shows the number of clients served by the home-care program, but only 27 percent (13) of the registers could be seen and confirmed. Only 11 of the 13 registers showed the number of clients. The number of registered clients varied between 5 and 873 (each register had a different number). Although complicated records are not necessary, this finding demonstrates the lack of adequate and clear management systems for home-based care.

To qualify for home-based care services, the patient must have a long-term illness (89 percent), or be in an advanced stage of a disease resulting from HIV (84 percent). Patients who receive these services have a broad range of physical, psychological, social, economic, and spiritual needs. A dilemma expressed by counsellors and home care providers was when to request home care services for clients. They said in many instances home-based care is referred to clients when they don't need it: at the time of posttest counselling when most are physically fit.

In all four districts, the most important needs of home-based care patients cited by care providers are: food (97 percent), drugs (84 percent), help with infection (70 percent), and emotional support (64 percent). Results of the survey also suggest that stigma exists in the interaction between home-based care providers and their clients and family members. More than two thirds (69 percent) of care providers said it is always acceptable to mention HIV/AIDS with clients. On the other hand, only 41 percent said it is always acceptable to mention HIV/AIDS in conversations with family members of clients.

Slightly more than half of these providers also cited need for clothes, money, and assistance in fighting stigma. This was confirmed in the focus group discussions in all places. In addition, both home caregivers and PLHAs, mentioned emotional needs, such as companionship, prayers, respect, and feelings of worthiness. Both groups mentioned the need for financial support to pay for transport and medical facilities, and to buy drugs.

Thirty-one home-based care respondents (71 percent) said the most important supplies they needed to provide service are food (61 percent), drugs (77 percent), financial support (81 percent), and gloves and soap (reported by an equal percentage of respondents). This information indicates that home-based care providers consider their safety and health as important as, if not more important, than their clients.

The capacity to refer clients from home-based care to medical or social support facilities was difficult or nonexistent. Although at the community level, care providers cited networking among various care provider programs within the community was good, referral outside the immediate community was hampered by lack of directories for "who provides what and where," and lack of involvement of others beyond the health sector. In the dissemination meeting participants expressed the need for the strengthening the referral systems between health facilities and community initiatives.

Home-care providers said they felt strengthened by their assignments. Home care, they said, creates community respect, and allows them to become a community confidante and learn beyond the biological knowledge of HIV. Home care work gives them an opportunity to speak about topics usually considered taboo, such as sex and death. But, they also expressed frustration in not being able to meet food and material needs. Many feel compelled to share what little they have; some give food, others medicine, and soap. The training in home care was highly regarded, but physicians raised the point that medical recognition of signs and symptoms that require referring patients for other services need to be emphasized more so that patients can be seen in time to treat appropriately their HIV-related illnesses.

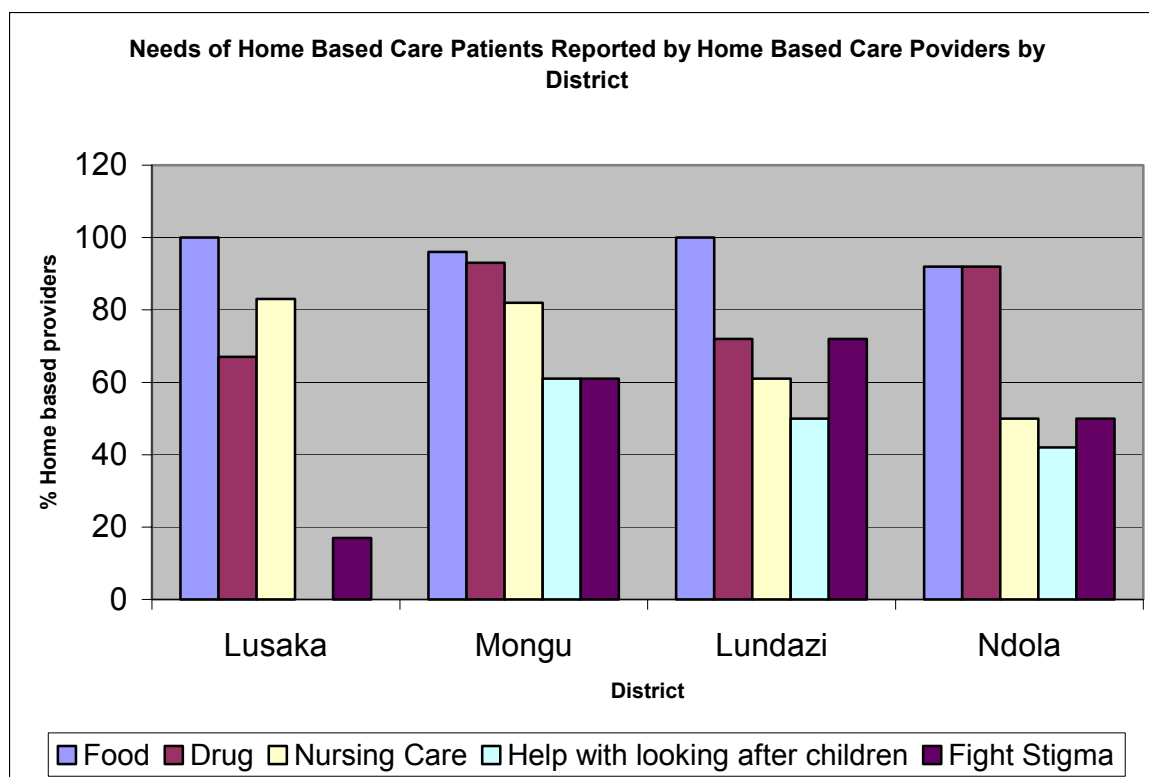


Figure 16. Needs of home-care patients reported by home-care providers in four Zambia districts.

Focus group discussions revealed a wide range of services provided to clients by health workers and community care providers. The services include voluntary counselling and testing, posttest club formation, home-based care and TB follow-up, palliative care, spiritual counselling, washing patients, giving medication, providing food from one's own and other sources, prayers, HIV/AIDS awareness and prevention, companionship, life skills training, and orphan care. Discussions revealed that persons living with HIV/AIDS provide counselling, HIV/AIDS awareness and prevention, promotion of positive living, networking for members, advocacy, stigma reduction, voluntary counselling and testing, home-based care, succession planning, and life skills training. Physicians who participated in focus group discussions expressed the increased need for home care, but cautioned that providers should be well trained to know when and where to refer clients as their conditions change. Referral should not be limited to medical issues, but should encompass all aspects of care and support. The clients doctors see have multiple needs (figure 16) that doctors and home care providers cannot address alone. These include access to transportation, drugs, food, supplies, counselling, legal support, succession planning, and livelihoods. Clients may often go for long periods without needing clinical or nursing care, which makes the home care provider the link to services in the care continuum. Community care providers confirmed the lack of community directories, but said referrals are based on informal information and individual relationships.

Strong networks exist primarily among health providers, such as clinical workers, doctors, hospitals, social welfare workers, and church workers. Multisectoral referrals—

education, agriculture, and employers—are not common. Networks work well at the community level when all partners are known to each other, but participants said referring clients outside of the immediate community was difficult. Another difficulty is that while care providers could identify a client’s need and the appropriate place for referral, services may not be available. This lack of services was a deterrent to referral because it raises a client’s expectations, and forces the client and the primary caregiver to spend time and money searching for services and resources that do not exist.

Focus group participants said training was one of the most important aspects of their involvement in community work. Some people said what they have learned has helped them work with others and changed their lives. Many expressed better self-esteem, respect in the community, and opportunities to share information with their family members, especially children. Many also said they have taken on a new role in the community—that of confidante. Because they have learned about confidentiality and stigma, people seek them for advice on many issues community health workers will not talk about, including premarital testing, how to treat genital herpes, and whether one can contract HIV by sharing the bedroom with a person who has TB. Although home-based care workers say working with clients in their homes is important and satisfying, the work of sharing information was also rewarding.

Only 41 percent of respondents reported that almost all clients had been tested for HIV, and 30 percent reported about half their clients had been tested for HIV. Six percent of respondents reported they did not know whether their clients had been tested.

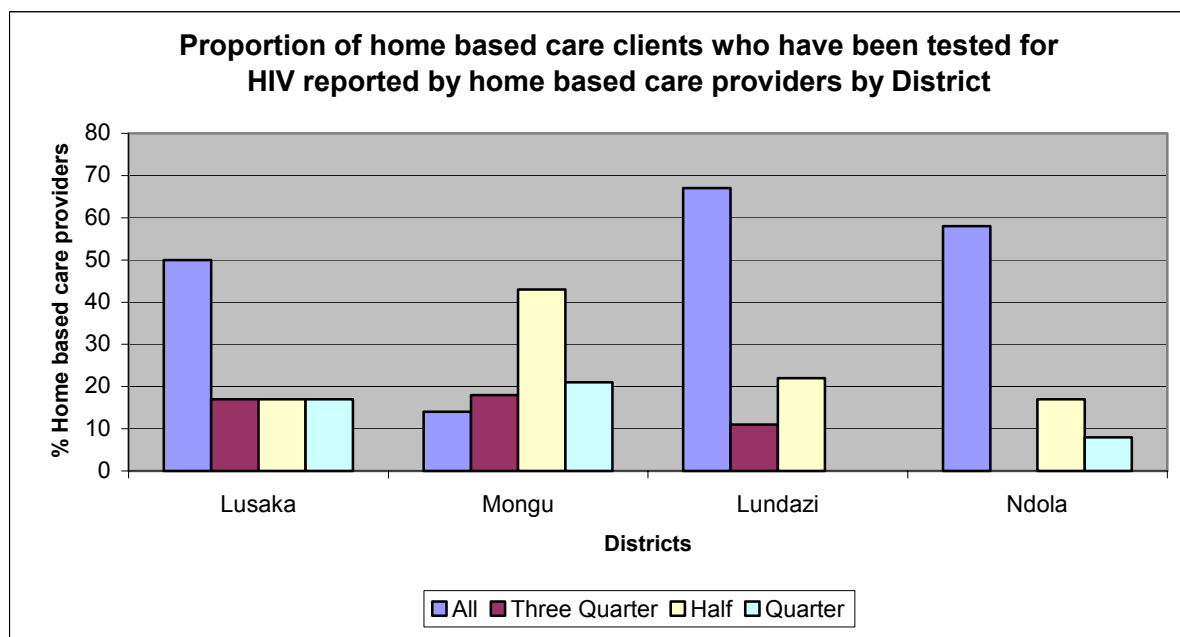


Figure 17. Proportion of home based care clients who have been tested for HIV reported by home-based care providers by District

5.10 Laboratory Services

Information about type of laboratory services, availability, access, and provision of services was collected and processed.

Five percent (29 workers) of all 545 respondents said they personally provide laboratory services at their facility. Eighty-six percent of respondents said their facility conducts syphilis tests, 69percent said they can perform a full blood picture, 66percent can perform a total lymphocyte count, 59percent can perform blood chemistry tests, 66percent can perform liver function tests, 66percent conduct HIV rapid tests, 69percent conduct HIV ELISA tests, 76percent conduct sputum smears, 79percent conduct Gram stains, 41percent perform an India ink stain, and 10percent can conduct CD4 FACS/Cytoflow tests.

Figure 18 presents the percentage of respondents who reported the type of laboratory tests performed at their facility.

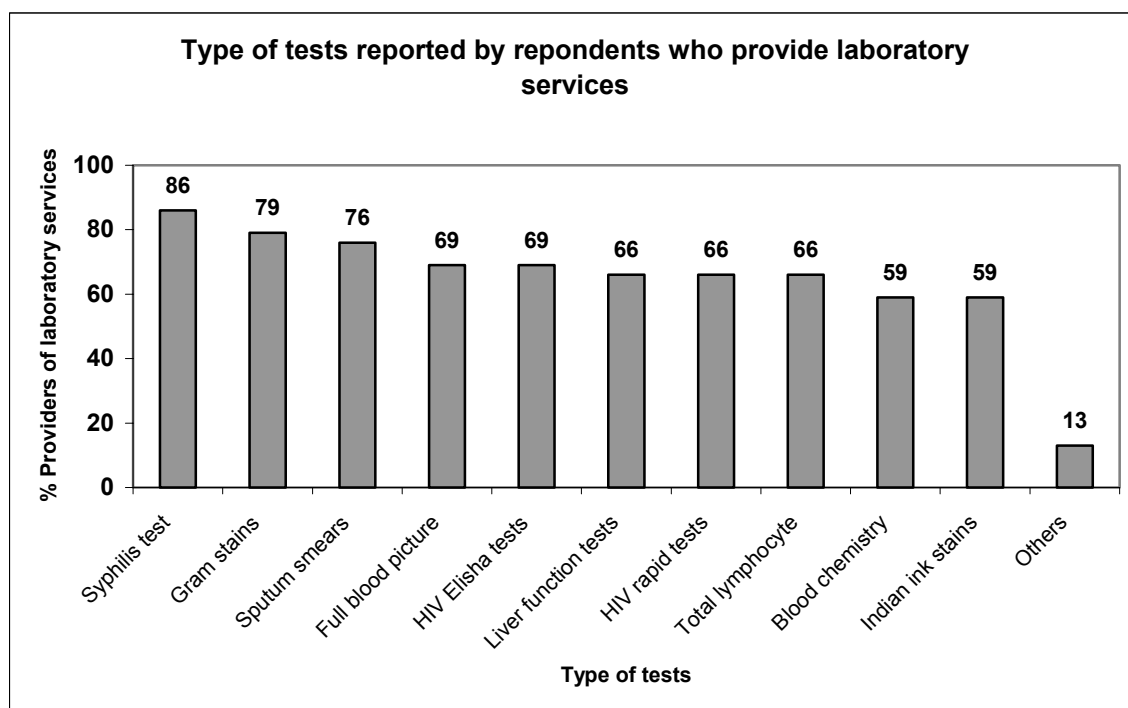



Figure 18. Type of tests reported by repondents who provide laboratory services

Only one respondent said their facility conducts CD4 alternative tests (Ndola Central Hospital), and another respondent said their facility conducts viral load testing (Kanyanga Mission Hospital). An additional 7 percent of respondents said their facility conducts Western blot analyses (Arthur Davison Hospital in Ndola  Kanyanga Rural Health Centre in Lundazi). When asked how long it took to obtain results of HIV antibody tests, 86 percent reported test results are available on the same day, 7 percent said test results are available the next day, and 7 percent said results are available within a week. In the

focus group discussions, participants agreed that results are available almost immediately, however, the distance to an outreach station and the resources (transport and food) needed for travel cause delay in giving client their results—“Sometimes it takes weeks.”

Twenty-four respondents (83 percent) said they refer tests to another laboratory. All respondents from general hospitals and all workers in Mongu and Lusaka Districts reported sending tests to another laboratory. Seventy-five percent of workers said viral load tests are always sent to another facility, followed by 67 percent of CD4 alternative microscope tests. Only 17 percent of respondents sent the full blood picture test for outside referral.

Thirty-eight percent of the 24 respondents said they refer total lymphocyte tests to other laboratories, 42 percent said they refer blood chemistry tests, 50 percent said they refer liver function tests, 42 percent said they refer HIV rapid tests, 46 percent said refer HIV ELISA tests, 54 percent said they refer sputum smears, 21 percent said they refer Gram Stains, 29 percent said they refer Indian ink stains, 63 percent said they refer CD4 FACS tests, and 58 percent said they refer Western Blot tests to other laboratories.

5.11 Confidentiality

Respondents were asked who had access to test results. Various precoded categories were given. Table 4 shows the results of these questions.

Table 4. Health care providers who have access to HIV test results

Person with Access to the Results	Health Workers Reporting Having Access to the Recorded Results (%)	Number of Health Workers
Superior	28	8
Fellow lab technicians	62	18
Nurses collecting results	31	9
Physician/clinical officer ordering tests	41	12
Other physicians, clinical officers	24	7
Counsellors	52	15
Self	69	20
Total	100	29

Sixty-nine percent of workers said they have access to recorded results, 28 percent said their superior has access to recorded test results, 62 percent said their fellow lab technicians have access, 31 percent said nurses who collect test results have access to results, 41 percent said physicians and clinical officers who order tests have access to recorded test results, 24 percent said other physicians and clinical officers have access, and 52 percent said that counsellors have access to recorded test results. Twenty-eight percent of respondents said they were aware of wrong reporting of HIV results due to errors in the system.

Forty-eight percent of respondents, who personally provide laboratory services, reported recording in the laboratory register, during the past month, requests for HIV testing from antenatal services. Thirty-one percent said they recorded requests from TB services, 24 percent from STI services, 55 percent from general medicine and outpatient departments, 21 percent from adult internal ward services, 17 percent from pediatric departments, 28 percent from another department in the facility, and 31 percent from outside the facility.

Focus group discussions revealed that participants thought voluntary counselling and testing was generally accessible and affordable (because it is free), but they also thought VCT was made inaccessible in areas where one has to travel a long distance to reach a testing center. Some areas provide counselling, but the testing center may be in another area. Participants said a full complement of voluntary counselling and testing services needs to be offered as close as possible to people's homes. Participants believe that where the services are not available in one place, confidentiality is compromised through the referral process.

There was consensus at all levels that confidentiality was respected in the provision of voluntary counselling and testing. Confidentiality is a primary concern of clients. Most respondents accepted the concept of shared confidentiality, the need for service providers to share their client's HIV status with other care providers, or example to have a viral load test or obtain a prescription for an ARV. The secondary provider automatically will know the status of the patient and is bound by the confidentiality vested between the first professional and the client. However, this "shared confidentiality" is at risk when the public witnesses a client go to a pharmacy to secure HIV drugs, a pregnant woman receive food supplements to carry home from the mother-to-child transmission clinic, or a person attend at a clinic for free medical services because they are HIV-positive. Clients should be fully apprised of shared confidentiality during the counselling process. They should be made aware that others may know their status as soon as they access HIV services.

It is now standard procedure in pretest counselling to encourage the client to inform someone close that they are going for a test. In one focus group discussion, a person living with HIV/AIDS shared concern about telling a partner about an HIV testing appointment and then returning later to share the test results. Respondents expressed the need for guidelines to be reviewed to ensure that rights of partners are protected. When looking toward the future, one doctor said, *"The time should come when we should tell patients about their malaria results and HIV results on the bedside, while other patients are listening."*

5.12 Pharmaceutical Services

Twelve percent of respondents reported they provide pharmaceutical services at their health facilities. The main sources of drug supplies for these facilities are the provincial or district stores (64 percent), followed by the central medical stores (28 percent), religious organizations (12 percent), and NGOs (11 percent). See Figure 20. A much smaller proportion of respondents reported that their facilities obtain drugs from private

donors (7 percent), foreign governments (7 percent), or private companies (4 percent). Most respondents (81 percent) who provide pharmaceutical services indicated they receive the essential drug package, however, less than half (44 percent) reported the package always arrives on time. Only one-third (34 percent) indicated the package is complete upon arrival.

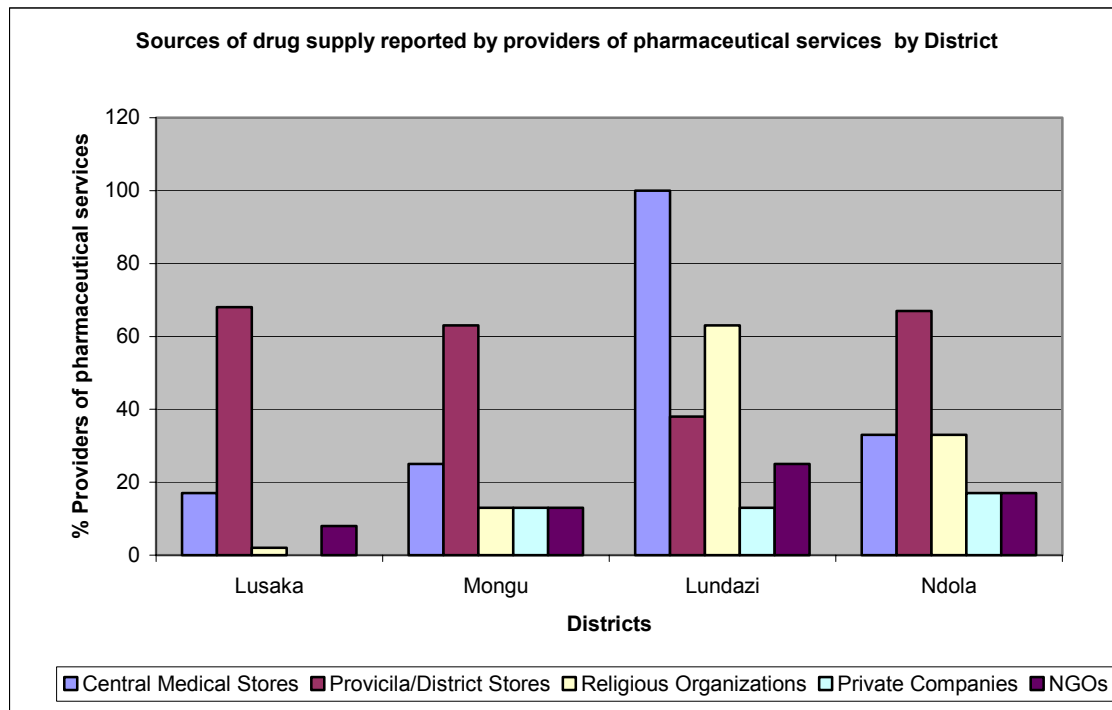


Figure 20. Sources of drug supply reported by providers of pharmaceutical services by District

All respondents who provided pharmaceutical services at various sites in Lundazi reported the TB drugs—rifampicin, ethambutol, pyrazinamide, and streptomycin—were in stock at the time of the survey (figure 21). In other districts, Mongu in particular, many respondents mentioned the unavailability of essential drugs for TB control. Worth noting: a vast majority of respondents mentioned streptomycin being out of stock.

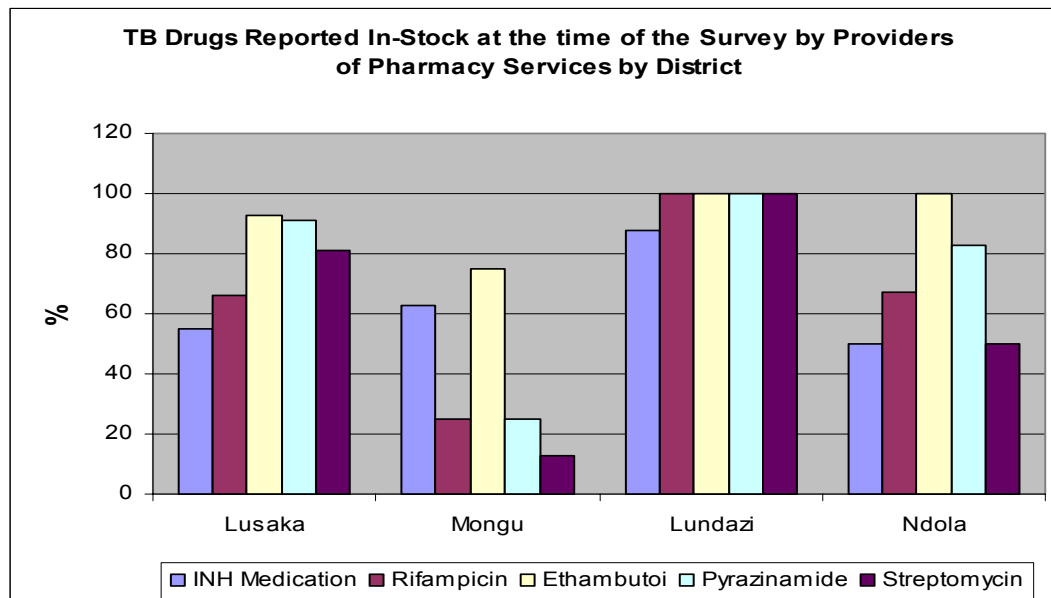


Figure 21. TB drugs reported in stock at the time of survey, by district.

Availability of TB drugs showed a wide variety, for e.g, INH and Streptomycin were being reported as often unavailable in at two districts.

Participants in the focus group discussions also raised the issue of drug affordability by PLHAs, including the essential TB drugs. Participants indicated drug requirements over time, even inexpensive drugs, absorbed substantial household expenditures. In all focus group discussions in all districts, the cost of drugs was an issue, and although the exemption possibility was mentioned, it is hardly used because it discloses the patient's serostatus to the drug dispenser.

Also discussed were the unavailability of strong painkillers and the irregular essential drug kit supplies, including TB drugs. Participants in all district focus group discussions expressed concern that Zambia' drug regulations prohibit peripheral health care staff from prescribing strong analgesics, such as codeine and oral morphine, for palliation in end-of-life situations.

I Interviews with the providers of pharmaceutical services revealed that only in Lundazi was strong analgesics available, and in Ndola only one mission health facility provided strong analgesics (figure 22). Surprisingly, from the referral hospitals the availability of strong analgesics was less frequently reported

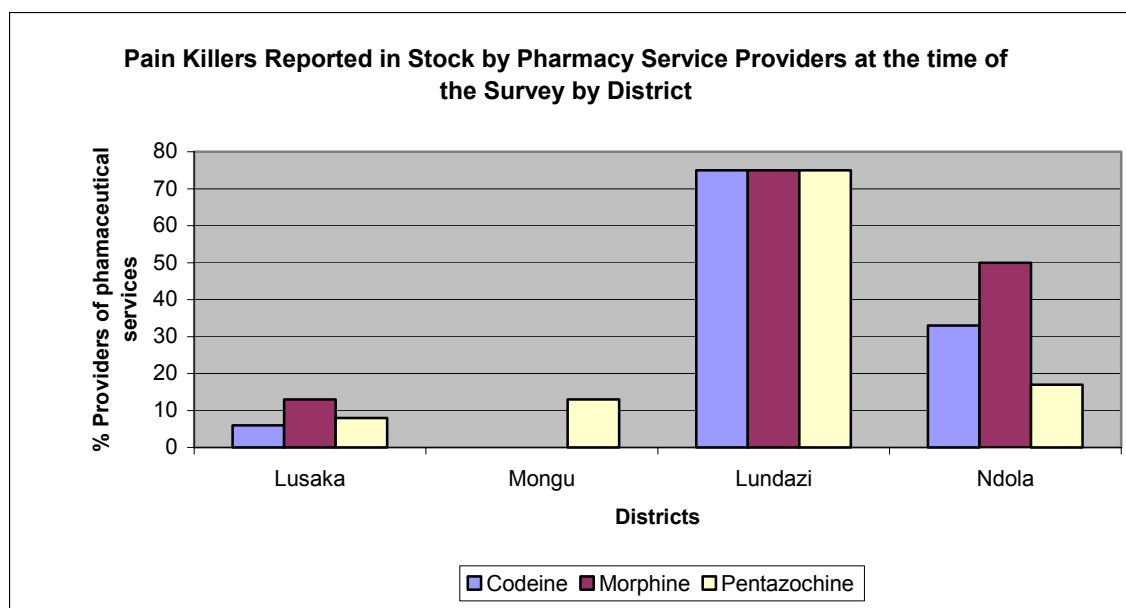


Figure 22. Painkillers reported in stock at the time of the survey, by district.

Less than one-third of the pharmacists reported having antiretroviral drugs in stock. From focus group discussions with home-based HIV caregivers and PLHAs came the awareness that ARV drugs are still clouded in mystery. Questions were asked such as: *“How do they look?” “Do they really cure?” “Are they only for the privileged?” “Are there strange side effects?”* These questions revealed that knowledge of what ARV can and cannot do is absent within the health system and within the community. Participants at some focus group discussions noted the current move to exempt all HIV-related drugs is unfair, as there are people in need who can easily afford them.

Participants in focus group discussions had a lot to say about drug supplies and antiretroviral drugs. They said persons living with HIV/AIDS are preoccupied with the availability of drugs and timely treatment. They said PLHA problems included accessibility—whether due to transport costs to get to the clinic, availability of drugs when prescribed, or home supply of basic drugs for emergencies, such as malaria or diarrhea. Although respondents believe universal provision of antiretroviral drugs is a human right, they noted special challenges—cost, logistics, transport, laboratory services, and trained staff—to overcome in making them. Respondents also said that if antiretroviral drugs were universally provided, donors should base the decision on a long-term policy and commitment of the government and not just short-term support.

In most facilities in Lundazi and Ndola, pharmacists reported the availability of fluconazol, an important drug for treating serious fungal infections, particularly esophageal candidiasis, and treating and preventing cryptococcal meningitis.

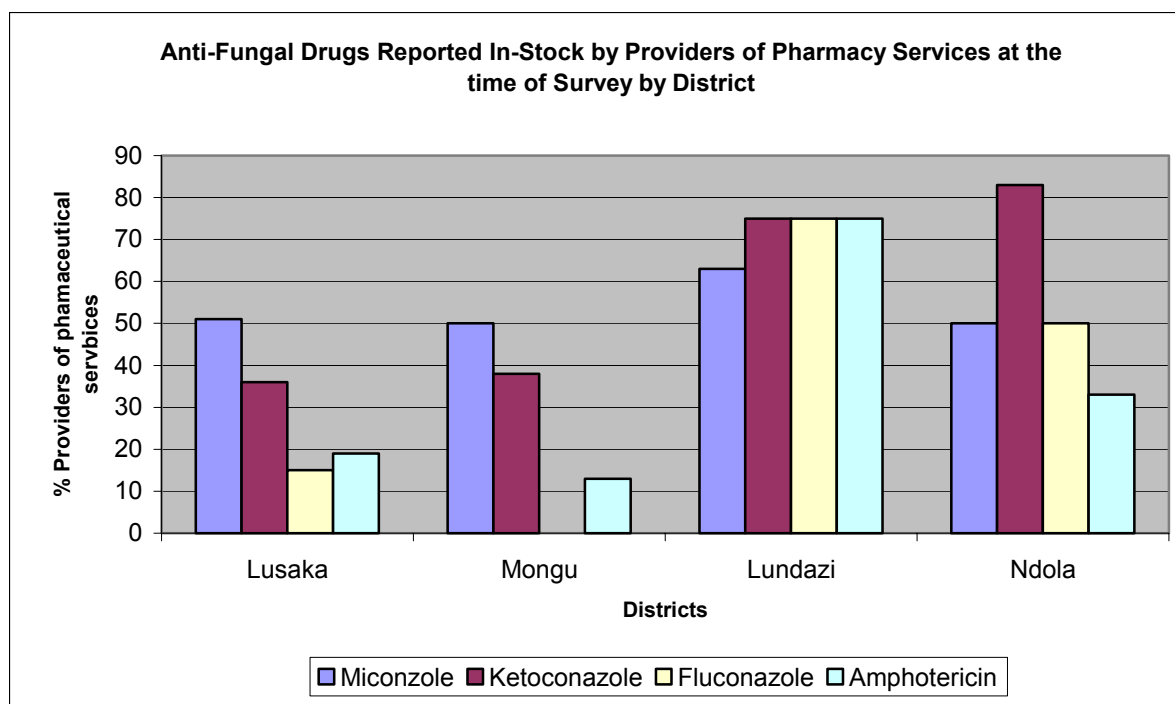


Figure 23. Percentage of pharmaceutical providers, by district, who reported an inventory of antifungal drugs.

In most facilities in Lundazi and Mongu, pharmacists reported the availability of Ketoconazole.

Nevertheless, antifungal treatment drugs are not as available as many of the antibiotics, probably because of higher costs and lack of orders due to the unfamiliarity of many clinicians with proper diagnosis of fungal disorders. Demand is thus underestimated. Expensive antifungals, such as amphotericin and fluconazole, are used regularly only during the later stages of care.

5.13 Updating Personnel

Respondents said they stay abreast of changes in drug regimens and usage through several informal methods, including colleagues (37 percent), journals (35 percent), and drug representatives (29 percent). Twenty-three percent of respondents said they read updates from the Ministry of Health. Training activities were not mentioned as a way to stay informed. Ninety-three percent are able to keep up-to-date by learning methods cited.

5.14 Focus Group Discussions on Drugs with Health Workers, Community Care Givers, and Persons Living with HIV/AIDS

When people talked of needs for persons living with HIV/AIDS, food, medicine, and finance were most prevalent. Concerns about medicines included accessibility and supply: distance to the supply center, payment of fees for those who does not disclose their status, and availability of medicine when a patient arrives at a clinic. People in remote rural areas felt powerless when they became sick at home without medicine and the means to do anything about it. In areas with home-based care programs, some community care providers reported having small amounts of over-the-counter drugs to offer their clients. This basic intervention made people feel they had somewhere to go for help. Even if they did not call on the community health provider, just knowing someone was accessible provided some peace of mind.

Home-based care workers, including professional nursing staff, reported antifungals often were used to relieve clients' symptoms. Anti-tuberculosis drugs are especially expensive and are beyond the means of most people. Home-based care providers said the need for drugs is overwhelming and the lack of drugs is a challenge.

5.15 Antiretroviral gs

Discussions with respondents at all levels revealed antiretroviral drugs were of great interest. Many people expressed divergent views about them. A summary of the main points is listed below.


- Community health workers and persons living with HIV/AIDS have heard of antiretroviral drugs but have not seen them.
- All respondents said antiretroviral drugs were neither accessible nor affordable. Most think they are accessible to and affordable by only the rich.
- All groups said they lack information about antiretroviral drugs, which is a major reason for not talking about them and thinking they are “out of reach.”
- Antiretroviral drugs are perceived to have major side effects, but the side effects are rarely discussed.
- The health workers believe confidentiality would be difficult to maintain once antiretroviral drugs are introduced in hospital settings because of the different stages patients go through.
- These drugs are seen as artificial. Although they prolong life, they also prolong suffering. In an in-depth interview, one man said his friend in Lusaka is on antiretroviral drugs. The friend told him that when you take antiretroviral drug, you feel good initially, then you get worse, so it is best not to start taking them at all.
- Health workers knew almost nothing about post-exposure prophylaxis.
- All groups recommended that in order to use antiretroviral drugs everything must be in place from the day you start until you die. Hence antiretroviral drugs and other logistical requirements, such as transport, laboratory services, and personnel trained in use of antiretroviral drugs, must be put in place.

- Health workers recommended drugs should be accessible as close as possible to those who need them.
- Health care workers question the government policy of providing free health services to persons living with HIV/AIDS, because some PLHA are able to pay for health care services.

5.16 Administration and Facility Management

Sixty-seven respondents, representing 52 facilities surveyed, work as administrator or manager of a health facility. These respondents provided insight into health care facility management and the ability of the facilities to deliver HIV/AIDS care and support services.

Health administrators identified common funding sources that included the government of Zambia (82 percent), local sources (40 percent), and NGOs (25 percent). Sixty-seven percent of respondents also reported patients pay attendance fees. Fees were also reported for laboratory services (60 percent), surgery (40 percent), and antenatal services (21 percent).

Focus group discussions with health workers, community care providers and PLHAs confirmed that HIV+ persons could access free medical services, but they had to disclose their HIV status to qualify and they were afraid of the resulting stigma. Focus group participants said  the health worker was personally aware of the client's HIV status, they would not charge for services. It was unclear how facility staff identifies who should receive free services for being HIV positive, except when the client presents a positive test result. Since patients are reluctant to reveal their HIV status, it is unclear how facility staff identify clients who qualify for free services.

Two thirds of administrators/managers reported their facilities have inpatient wards. During the year prior to this survey, those with AIDS-related illnesses occupied about 65 percent of the female inpatient beds and 60 percent of the male inpatient beds. Most administrators (79 percent) reported ambulatory patients with known HIV-related illnesses attend the general outpatient clinic at their facilities, the VCT center (31 percent), or a home-based clinic (30 percent).

Almost all (90 percent) of the administrators/managers said that TB treatment is offered at their facility. STI services were also commonly mentioned (88 percent). A much smaller proportion (24 percent) indicated that MTCT services are provided. The survey suggests very few facilities provide post-exposure prophylaxis for clinical staff that may have had "needle-stick" injuries or other exposure to HIV. Only 19 percent of respondents said the facilities where they work offer such services to staff.

Sixty-seven percent of administrators/managers said VCT services were available at their facilities. Among this group, 62 percent described VCT services as integrated with the outpatient department, antenatal care, TB, STI, and general medical services. Almost all

of these facilities, according to 91 percent of respondents, have separate VCT service units.

Health facilities represented by the administrators surveyed provide a range of support services for HIV-positive persons and their families. The most common service, mentioned by 72 percent of administrators, was home-based care. Less than one-third of the respondents indicated their facility also provides support through posttest clubs (28 percent), food support (27 percent), orphan support (13 percent), and spiritual support (8 percent).

Improving the skills of staff to provide HIV/AIDS care and support is usually done through in-service training. Thirty percent of administrators surveyed said HIV training is provided for staff, and 18 percent indicated they provide HIV/AIDS training for medical staff, clinical officers, and nursing students.

National guidelines on various aspects of HIV/AIDS care and support were not universal in the health facilities. Less than half of administrators reported their facility follows national guidelines on MTCT (49 percent), clinical management of HIV/AIDS (48 percent), VCT (45 percent), HIV/AIDS reporting requirements (39 percent), and home-based care (27 percent).

In Zambia, District AIDS Task Forces provide an avenue for planning interventions to respond to the HIV/AIDS pandemic. District Health Management Teams convene AIDS task forces to plan projects in accordance with the National Strategic Framework on HIV/AIDS. Twenty-four percent of the administrators indicated the facilities where they work have received guidance on the Zambia AIDS Strategic Plan from the NAC. Twelve percent of these respondents said they had participated in HIV/AIDS planning with the District AIDS Task Force, and 22 percent said they had participated in HIV/AIDS planning with the District Health Management Team. Figure 24 shows that medical facilities often are not regular partners in the district health planning process. In focus group discussions, participants reported hospital staff does not take part in these activities. They expressed concern that hospital administrators are not involved in HIV/AIDS planning with either the DHMT or the DATF. They believe that even though hospital personnel has many demands on its time, the staff would have much to offer the DATF in developing strategies in the community to address HIV/AIDS from the planning stage to implementing activities that provide a continuum of care.

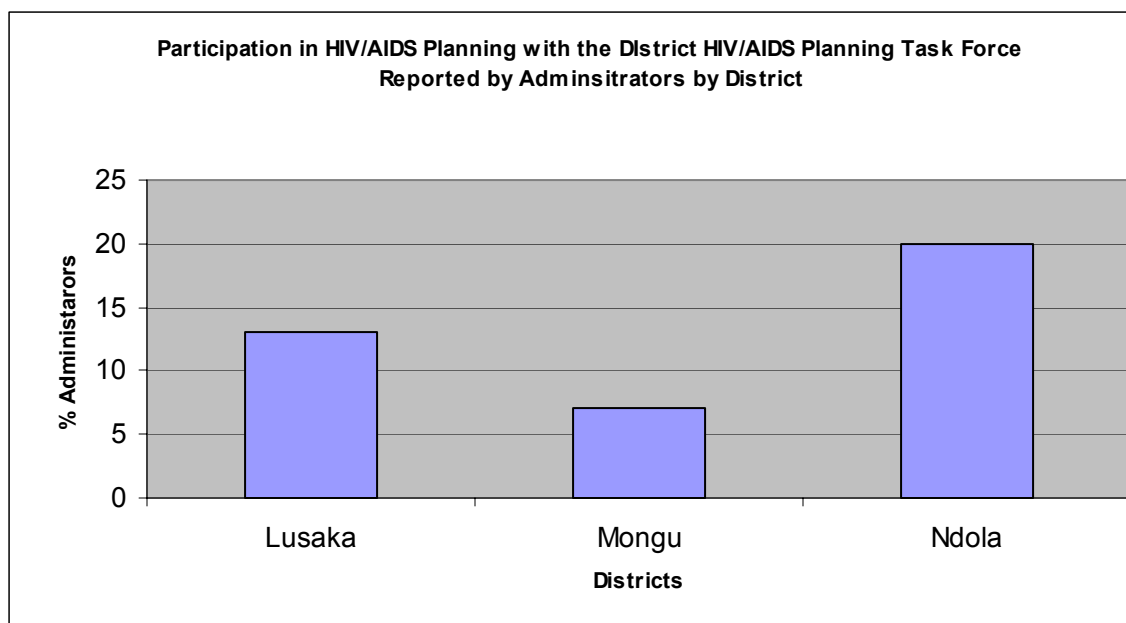


Figure 24. Percentage of administrators, by district, who participate in the District HIV/AIDS Planning Task Force

When asked about the greatest obstacles to improving and expanding HIV/AIDS care and support in the facilities where they work, insufficient training (72 percent) emerged as the most common obstacle. Other obstacles mentioned by more than half of respondents included staff shortage (66 percent), lack of HIV/AIDS guidelines (57 percent), and low salaries (52 percent). Thirty-three percent of respondents said the greatest obstacle to improving and expanding HIV care is acceptance by staff and 37 percent of respondents said acceptance by the community. Lack of administration involvement in District planning was not viewed as an obstacle to effective service at district level.

5.17 Stigma

It is widely acknowledged that HIV/AIDS-related stigma is both widespread and a significant obstacle to the provision of effective care and support measures. Stigma can occur at several different levels: political, institutional, social, and psychological. All respondents were asked a series of questions to determine the level of HIV/AIDS-related stigma within care and support services. Stigma was described as *“a scar that you cannot get away from.”* Others described it as being *“labelled as a person who has been doing ‘that thing.’”* It is *“something very bad, which is like a stain in the mind, like being HIV positive. It is how he is thinking inside him.”*

More than two thirds (70 percent) of respondents said they spend more time with a patient with suspected HIV-related illness compared with a patient with another illness.

Testing and receiving test results is a sensitive process and could signal the beginning of HIV-related stigma, especially if an individual tests positive. Among HIV care providers, 25 percent said it is their job to disclose HIV test results to patients. Among all doctors, 48 percent disclose test results. Only 17 percent of clinical officers reported they disclose

test results. However, 31 percent of registered nurses, and 21 percent of nurses provide test results. Among these respondents, 69 percent said the last time they informed a patient of his or her HIV status occurred within the previous month. The last time a positive test result was given to a patient, 10 percent of respondents said they also involved a doctor, nurse/counselor, or spouse; 8 percent reported that a family member was involved.

During focus group discussions, some persons living with HIV/AIDS reported disclosing their HIV status to relatives, their ZNP+ group, and their counsellor. In Mongu, however, disclosure of HIV status is not common and only a very few people indicated they had disclosed their HIV status. People do not normally talk about their status. Many persons living with HIV/AIDS believe disclosure of results should be left to the patient. One person said, “(HIV) is something I have and not anybody else, so it is my right to talk about it to whomever I choose. If you did not take me for the test, it is nothing to you.” Health and community care providers in focus group discussions also expressed this view.

LIVING WITH HIV/AIDS: A PERSONAL EXPERIENCE

Winston Zulu

I first took an HIV test in 1990. At that time knowledge about AIDS was relatively limited and I thought if one is infected, he had only five years to live. Then, there were fewer AIDS services aimed at people living with HIV/AIDS. AIDS was completely invisible, as there was no one who had come out as a person living with HIV/AIDS in the country. Almost all messages, whether on print or electronic media, were geared toward prevention. Many of them were nasty. It was in this atmosphere that I was pronounced HIV positive, without any counselling.

Before testing, I had been awarded a scholarship to study in the Soviet Union. My personal ambitions went into disarray immediately. I wanted to study politics and I could not. HIV-positive prospective students were not allowed in Russia. Worse still, I had shot my mouth all over the place about my scholarship, and then I had the task of explaining why I couldn't go. Life would have been different if I had not taken that test. An HIV-positive result does change your life. This is especially so if you decide, like I did, to be open about it. Ignorance, coupled with society's hang-ups with issues of sex and death, breeds intense stigma and discrimination. It was around this time that I encountered Kara Counselling and Fr. Michael Kelly. I was helped to see things differently and discovered inner resources that I didn't think I had. Together we set up what we called "Group Outreach Counselling Programme". The programme was later dubbed "Positive and Living Squad" (PALS). The programme was a big success and made Kara move from being merely a project into a full-fledged NGO. We got recognition from the head of state and received a number of awards, including the \$7000 NORAD award "It Works" for 1991.

PALS was also largely influential in the formation of the Network of African People Living with HIV/AIDS (NAP) and the Network of Zambian People Living with HIV/AIDS (NZP+) through efforts of David Chipanta.

Twelve years experience of living with this virus has convinced me that the problem is not so much HIV but society's reaction to it. I know that you can live a normal life with the infection if you keep your mouth shut. You only need to avoid the test to be assured of dying of an "illness"

not AIDS. Then again, you are still likely to face stigma when you are visibly ill, but at least that will be then, not right after the test results.

I deeply regret catching this infection, but my biggest sorrow is the fact that I was honest enough to publicly declare that fact. There is so much stigma and discrimination. Although most people are familiar with workplace discrimination or travel restrictions to such God forsaken places in the 'developed' countries, the most painful form of discrimination is much less pronounced, more surreptitious. "No beer, no smoking, no marriage, no sex, no red meat, no processed sugar, no Coca-Cola" - no way! Suddenly, everyone expects you to be holy just because you are HIV positive. The kind of life expected of one when one tests HIV positive makes dying of AIDS look like a kindergarten picnic.

Living with HIV is also fraught with many personal dilemmas. Do you tell everyone close to you? What about sexual partners? Does having children when you know you are HIV- positive a human right or an irresponsible act? If it is a right, what about the right of the child? Is the promotion of PMTCT a license for PLHA to have children? In the same vein, is the promotion of condom and the development of microbicides and HIV vaccines promoting promiscuity? These dilemmas and ethical questions confront all people affected by HIV/AIDS. But they take on a completely different dimension to a person infected with the virus. A person who volunteers to take the HIV test makes the ultimate political statement that he or she is committed to the fight against AIDS in a very personal way.

The positive part of this is the development of counselling services in Zambia. We now have a better-trained cadre of counsellors able to deal with these complex issues in almost all parts of the country. There is a better appreciation of the link between human rights and health. There is a greater understanding of PLHA needs and strengths in this horrible fight against AIDS.

At Kara Counselling and Training Trust, it is now standard procedure in pretest counselling to encourage the client to inform someone close that they are going for a test and to have someone with whom to share results. One person living with HIV/AIDS expressed concerns about telling a partner about an HIV testing appointment and returning later to share the results with the partner. In this situation, the partner was being tested without counselling.

Disclosure of HIV diagnosis to close relatives of patients who are discharged from the hospital with late-stage clinical AIDS was not common among the health care workers surveyed. Only 9 percent indicated family members were informed of the HIV/AIDS status of the patient when released from the hospital. Patients are usually released if they improve clinically or recover (59 percent), or after agreeing to home-based care (20 percent). Most respondents (61 percent) thought that the current quality of care for patients at their facility was better than before; 20 percent thought it had remained the same. Sixteen percent believed the quality of care had declined at their facility.

Health care providers described the psychological impact of HIV status disclosure on patients in different ways. Only 30 percent of respondents described the patient as "easily accepting" the test results. Seventy percent of respondents described the patients as "depressed, with suicidal tendencies," 57 percent described the patients as being "in

denial," and 42 percent said their patients often develop a feeling of "blame and condemnation" following a positive test result.

Just less than half of respondents (44 percent) said "very few" health care workers know their own HIV status. Most respondents (73 percent) reported the reason so few care providers go for counselling and testing is fear of the reactions of colleagues, friends, and family. Another reason given (47 percent) was that there is no point in knowing one's HIV status if ARV treatment is not available. This sentiment is consistent with findings from focus group discussions held with health care providers, who reported health personnel were the worst when it comes to dealing with being HIV positive.

Less than half (48 percent) of respondents indicated that their facilities had health worker protocols or guidelines on how to avoid accidental HIV infection. Health workers indicated no significant difference in behavior when examining or washing a patient with HIV versus a patient without HIV. In both cases, most respondents said they wear gloves when examining an HIV-positive patient (86 percent) or a patient without HIV (83 percent).

When asked whether availability of ARV and treatments for Ois [what type of disease is this?] would reduce stigma, the following responses about ARVs resulted. About 5 percent of respondents reported they have access in their facility to antiretroviral drugs to help prevent infection after exposure to HIV. Only a small difference exists between registered nurses (6 percent), nurses (5 percent), clinical officers (4 percent), and doctors (3 percent) who reported access to antiretroviral drugs. More respondents from Ndola District (10 percent) and only 1 percent from Mongu District reported access to antiretroviral drugs. None of the respondents from a general hospital reported access to antiretroviral drugs. Low access to antiretroviral drugs is confirmed by results from focus group discussions. Only a few participants had any knowledge of antiretroviral drugs, or how to access them. In some cases, they confused antiretroviral drugs with immune boosters.

Only 18 percent of respondents reported availability of support services to help care providers to deal with burnout associated with caring for HIV/AIDS patients. More respondents from mission hospitals (83 percent) and only 8 percent from urban health centers said support services were available. Respondents from Lundazi District (55 percent) were more likely to report availability of support services than those from Ndola District (28 percent), Mongu District (19 percent), and Lusaka District (17 percent).

Kinds of support included talking to colleagues (72 percent), counselors available for staff (62 percent), staff allowed to take sick leave (50 percent) and other means of support (12 percent), which included talking to fellow counselors and occasional leave.

Most respondents (74 percent) thought, compared with the past, the attitude among staff within their facility had improved toward patients with suspected HIV-related illness. This improvement resulted from acceptance of HIV/AIDS as part of their job (88 percent), and reduction in stigma of HIV/AIDS patients (60 percent).

Confidentiality was an issue in all focus group discussions. Confidentiality is difficult to attain in facilities that do not have a separate room available for counselling. Most respondents (68 percent) said their facility had separate space for counseling. Stigma is disappearing with education. Feelings are largely kept internal, due to the sexual mode of transmission and the fact that AIDS still has no cure.

In rural districts, very few, if any, persons living with HIV/AIDS have revealed their illness to others. Reasons for keeping silent include denial, feelings of shame, and fear of rejection. Some persons who have shared their HIV/AIDS status said they later might regret having done so because of reactions from other people. In one group a participant said, *“There is no reason for a test. ... with poverty one cannot change certain risky behaviours (sex for a living—access to food, clothes) until there is the financial support to live.”* One woman said, *“Your spouse can stop you from having a test.”*

5.18 Supervision

Two thirds of the 545 respondents reported they are supervised regularly on the job. In the three months prior to the survey, these health care workers were visited by their supervisors an average 21 times. However, about a fourth (24 percent) of them were visited by their supervisor only once during the same three-month period. Respondents cited the following reasons for the most recent supervisory visit: to discuss work-related problems (76 percent), to observe job performance (72 percent), to review reports (63 percent), and to provide work-related technical updates. Respondents who reported that their supervisor visited them indicated the supervisor provided helpful information on how they were doing in their job.

Most respondents who are supervised mentioned that one or more components of supportive supervision (observation, reviewing reports, and discussing problems) were provided.

Respondents were asked about limitations to performing their job. While respondents find supervision helpful, they face many overriding challenges in performing their job. Seventy-eight percent of respondents reported staff shortages, followed by 65 percent reporting lack of supplies and 58 percent reporting lack of adequate training. Other challenges to job performance include: lack of time (27 percent), lack of adequate supervision (13 percent), and people who do not use the facility (because they cannot afford the expenses related to coming for treatment – child care, transportation, food, no energy to walk to the clinic) (12 percent). About 59 percent of respondents reported demoralized staff, lack of feedback on performance (32 percent) and lack of transportation for patients (51 percent). About 69 percent of respondents reported inadequate salary, followed by inadequate facilities (52 percent) and a poor working environment (44 percent). Nearly 56 percent of respondents reported lack of adequate training as the most difficult problems in doing their job, followed by poor security (28 percent), and political interference and corruption (22 percent). Fifty-eight percent of respondents said the most difficult part in doing their job was having too many patients.

5.19 Responses from Focus Group Discussions on Care and Support Service Environment

During focus group discussions, health providers highlighted tremendous workload, inadequate salaries, and demoralized staff as the most serious challenges they face in their work. Due to inadequate salaries, staff members do additional work to supplement their income, such as work for NGOs (home-based care and counselling), or in private clinics, but even this additional work is not enough to address their basic financial needs. They believe no matter how much work they do; it is never enough to make a visible impact on the provision of service.

Despite the difficult working conditions of health workers, they were greatly concerned about problems in the quality of service delivery, including transportation.

Respondents expressed concern that other researchers had come before and asked the same questions. Respondents had explained the same problems, but they received no feedback and nothing happened to improve their situation.

Community care providers ranked high, as a challenge to their work, the neglect of HIV/AIDS patients due to poverty and ignorance, or because the patients alienated themselves when they were well. Other challenges included the shortage of food for patients and inadequate transportation for taking patients to hospital. When asked what could be done, community care providers thought they could engage in IGAs to support their community activities and to help the households of PLHAs. Umbrellas and seminars for community care providers and patients' families were cited as simple incentives for providing services in the community.

Among persons living with HIV/AIDS, high ranking challenges included getting people to accept their status, going for voluntary counselling and testing, neglect of HIV patients, lack of food and financial support, people not changing their behavior, , inadequate transport for getting sick people to hospital, and having a disease that has no cure.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

VCT and care and support stakeholders in Zambia developed the recommendations in this section in a series of meetings. The results from the study were reviewed and further analyzed in a stakeholders meeting that included participants from the districts where the assessment took place, members of working groups for OVC, STI, IEC, PMTCT, and VCT, funding agencies, and other health officials in Zambia. Based on the results of the assessment, the recommendations identified standards for comprehensive HIV/AIDS care and support in Zambia, a district level care and support package, as well as national recommendations for the National AIDS Council.

6.1 Zambia Standards for Comprehensive HIV/AIDS Care and Support

The following were recommendations were made towards a comprehensive HIV/AIDS care and support package in Zambia.

- HIV care and support to be comprehensive: meeting medical, nursing, psychological, nutritional, social, economic and spiritual needs, while respecting client rights and promoting prevention opportunities throughout
- Care providers to embody empathic attitudes, respect, and compassion
- Comprehensive care to extend beyond the individual to the family or household
- Comprehensive care to extend beyond the ill to asymptomatic infected people and address nutrition, prevention, and emotional needs
- A key entry point to prevention and care and support to be voluntary, counseling, and testing
- Medical services to include acceptable, affordable, and standardized preventive therapies; management of HIV-related illnesses and opportunistic infections; DOTS for HIV/TB; laboratory services; highly active antiretroviral therapy (HAART); post-exposure prophylaxis (PEP) for injuries and rape; STI management; and palliative care
- Reproductive health services to include VCT, antiretroviral drugs to reduce mother-to-child transmission of HIV, safe labor practices, follow up care for HIV-positive mothers and infants, infant feeding counselling and family planning
- Workplace safety to be ensured at each health care facility for staff and patients, including care for the care providers and opportunities for VCT for staff at relevant places
- Health and community care providers to have relevant counselling, communication, and supervisory skills, through adequate training and follow-up training as per national policies, guidance, and norms
- Care services to be delivered across a continuum of care from home-care programs and organizations to facility programs and back through functional referral and feedback mechanisms with client's consent
- HIV care planning to involve all sectors—line ministries, NGOs, faith-based organizations, and CBOs—with particular attention to be given to vulnerable groups and gender issues
- PLHAs to be involved in planning and implementation

6.2 Zambia HIV/AIDS Care and Support District Package

- A functional and multisectoral DATF with mandated planning, coordination, and dissemination responsibilities answerable to district authorities
- Ongoing partnerships through DATF between public health, hospital, private, faith-based, nongovernmental, community-based and home-care programs, and organizations and providers of comprehensive care and support
- Updated directories of HIV care services—who does what and where across a continuum from institutions to community-based and home-care programs
- Accessible and affordable facilities for physical therapy, opportunistic infections management, STI, HAART, PEP, and palliative care
- Health care facilities that address care for the HIV care providers
- District health plans that support to health programs that include activities to scale up VCT, MTCT and home care
- VCT activities that include active referral to care and support (VCT PLUS), links to MTCT, promotion of couple counselling, and opportunities for health care staff to learn their serostatus
- TB-DOTS activities linked to VCT
- MTCT activities integrated with VCT and Reproductive Health Services
- Accessible facilities to address needs of HIV asymptomatic people, such as reproductive health, nutrition, healthy life styles, and preventive therapies
- Nutritional support activities for families affected by HIV to be addressed by relevant district bodies
- Training activities for each care provider cadre that reflect specific needs in care and support
- Expanded availability of drugs, particularly, antifungals, strong analgesics, and antiretrovirals
- Promotion of government policy of fee exemptions to HIV/AIDS
- Management and referral systems to support the continuum of care
- Availability of guidance materials and national policies and standards for HIV/AIDS at all health facilities and HIV/AIDS programs
- Monitoring and health management information systems in place for HIV/AIDS care and support activities

6.3 National Recommendations

The VCT and Care Technical Working Group propose the following recommendations for the National AIDS Council

15. Adopt the Zambia Standards for Comprehensive HIV/AIDS Care and Support and the Zambia Essential HIV/AIDS Care and Support District Package and incorporate them into the National HIV/AIDS/STD/TB Strategic Framework
16. Include counselling skills in the preservice training for all categories of nurses

17. Provide training in communication skills to doctors and clinical officers that offer HIV/AIDS diagnostic and treatment services to improve their ability to 'break bad news' to clients
18. Continue to educate clinical care providers to meet the challenges of HIV/AIDS clinical management and care provision. Revise curriculum for pre- and in-service training to address preventive therapies for opportunistic infections, management of all AIDS and HIV/AIDS-related illnesses, the safe and effective use of antiretrovirals, issues of drug adherence to long-term drug taking, and referral mechanisms
19. Give providers of clinical care, counselling, and home care access to up-to-date, relevant, and appropriate national guidelines and learning materials
20. Recognize counselling a profession, with all its benefits and responsibilities
21. Include in the Zambia Essential Drug Package antivirals, for example, acyclovir; antifungals, for example, fluconazole; analgesics, for example, codeine and oral morphine; and antiretrovirals, including HAART
22. Lobby for the adoption of a parliamentary act that will make strong analgesics, such as codeine and oral morphine, available for palliative care to relieve the pain and suffering of those with afflictions related to HIV
23. Include in the guidelines of the District Aids Task Force, the following roles and responsibilities:
 - a) The DATF to be answerable to the District Development Coordinating Committee; and
 - b) The DHMT to act as the secretariat for the DATF
24. Include total lymphocyte counts and alternative CD counts in district-level laboratory services to meet the current needs related to HIV/AIDS care; strengthen systems for quality assurance at all levels
25. To assist with the current staff shortages and health services overload, promote strategies that focus on early disclosure (with the consent of the client) to significant others, such as a trusted relative, parent, sibling, children, and/or partner to
 - a) Help clients to cope better;
 - b) Encourage clients to seek assistance earlier for opportunistic infections and other HIV/AIDS-related conditions;
 - c) Assist patients to adhere better to drug treatment; and
 - d) Share future planning for children

26. Incorporate data on AIDS and HIV/AIDS-related illnesses in routine records and reporting systems to strengthen Health Management Systems at all levels
27. Develop practical and feasible systems for supervising institutional clinical HIV/AIDS care, counselling, and home care services
28. Promote partnerships between various institutions and programs that provide care and support services to collaborate better and design referral mechanisms for clients across a care continuum from home to community to facility and back.

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